

**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, AND EDUCATION, AND  
RELATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2008**

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U.S. SENATE,  
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,  
*Washington, DC.*

**NONDEPARTMENTAL WITNESSES**

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

**PREPARED STATEMENT OF THE ACADEMY OF RADIOLOGY RESEARCH**

This statement is submitted on behalf of the Academy of Radiology Research, an alliance of 23 scientific and professional societies with a membership of more than 40,000 radiologists, imaging scientists, and allied professionals. The Academy is also supported by national organizations representing more than 100,000 radiologic technologists.

In addition, I am also representing the Coalition for Imaging and Biomedical Engineering Research (CIBR). CIBR is a permanent coalition of radiology, imaging, and bioengineering societies; imaging equipment and medical device manufacturers; and patient advocacy groups. What unites all of these diverse groups is the common recognition that new imaging and biomedical engineering techniques and technologies can transform medical science and produce dramatic improvements in the detection, diagnosis, and treatment of a broad range of diseases and conditions.

The purpose of my statement is to urge the Appropriations Committee and Congress to make an investment this year that will foster innovation in imaging and produce a new revolution in medical science and health care driven by technology development. Recognizing the significant budgetary challenges we face at present, it is critical that the Federal Government take full advantage of the scientific opportunities that offer the best prospects for improving the capability of physicians to diagnose and treat a broad range of diseases and conditions. Imaging is one such area of scientific opportunity. For that reason, we request that the committee increase the appropriation in fiscal year 2008 to \$350 million for the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the newest Institute at the National Institutes of Health and the primary home for basic research in imaging at the NIH.

The NIBIB is not the sole home for imaging research at the NIH. Indeed, the National Cancer Institute was the primary supporter of imaging in the years before the NIBIB was established. With strong support from NCI Director John E. Niederhuber and leadership from Dr. Dan Sullivan, the NCI Cancer Imaging Program continues to grow and push the boundaries of knowledge. I hope that the committee will support the growth of NCI initiatives in areas such as imaging as a biomarker for drug development, the development of new image-guided ablative therapies, and computer-assisted methods of combining imaging and other clinical data.

While the extramural community strongly supports imaging research programs at the NCI and other Institutes, the NIBIB is the Institute charged with developing new imaging techniques and technologies with broad clinical and research applications. Investing in the NIBIB yields dividends for all of the other Institutes in the form of new tools for studying the specific diseases that constitute the missions of

those Institutes. It also pays large dividends for patients, who will benefit from new imaging techniques that improve medical care and reduce the need for more invasive, painful, and expensive procedures.

A good example is the first grant made by the NIBIB in 2002—a Bioengineering Research Partnership award to a multi-institutional group led by Dr. James Duncan of Yale University. With this support from the NIBIB, Dr. Duncan and his team have been developing new, image-guided surgical techniques for treating patients with certain, severe forms of epilepsy. The results have been dramatic. A patient who has undergone this surgery recently told the House Medical Technology Caucus that the number of seizures she suffered daily dropped from more than 30 to zero. After years enduring a severe disability that affected virtually every area of activity, she was suddenly given her life back.

As with many imaging research projects, however, the longer-term payoff will be much greater. This research is producing data from the brain that is helping scientists to understand brain structure and function in general. Moreover, this new information about the brain will improve our understanding of Parkinson's Disease, autism, Alzheimer's Disease, dementia, and other disorders. Finally, the techniques developed with this grant could have much broader applications, such as the use of imaging to guide cancer therapy to destroy tumors or to deliver drugs to precise locations in the brain in order to treat a variety of neurological disorders. Thus, a project to improve the lives of epilepsy patients will eventually produce new treatments for many more people with a range of neurological disorders. This is typical of NIBIB and imaging initiatives.

The NIBIB, is different from other Institutes. As NIBIB Director Roderic I. Pettigrew has observed, "In other Institutes they utilize tools. In this Institute, we discover tools." These tools are used by investigators at the other Institutes both to improve our understanding of disease processes and as a principal component in new therapies. Optical imaging, for example, is an emerging technology that uses light waves to produce high-quality images. Based on early research, the use of optical imaging to diagnose and treat breast cancer appears to be especially promising. This technology may allow physicians to investigate large sections of tissue rapidly for cancerous growths, to guide surgery to remove tumors, and to scan effectively for additional disease. As optical imaging develops, physicians and scientists will have a new tool with applications to a wide spectrum of diseases. It also promises to be safer and less expensive than earlier technologies.

The last Congress overwhelmingly approved the National Institutes of Health Reform Act of 2007, which called for a renewed emphasis on trans-NIH research and a special focus on research at the nexus of the physical and life sciences. NIBIB is well positioned to make good on Congress's intent in both areas. The NIBIB, by its nature, is perhaps the most collaborative and interdisciplinary of all the Institutes and Centers at the NIH. In its first years, the NIBIB has pioneered collaborative projects with other Institutes to develop new techniques with applications to specific diseases. NIBIB is also NIH's most prominent "bridge" to the physical sciences. Three examples clearly illustrate NIBIB's unique collaborative roll.

#### IMAGE GUIDED INTERVENTION

Despite its prominence in modern-day medicine, surgery remains in a relatively primitive state. Although improvements in surgical techniques abound, costs are high, invasive procedures are still the norm, and surgeons continue to rely on pre-operative images. Significant improvements to the current state of surgery are well within our reach. Highly exacting image-guided intervention could potentially minimize invasiveness, greatly reducing patient recovery time and the costs associated with it. With the acquisition and use of real-time (moving) 3D images, surgeons will move far beyond pre-op images to observe blood flow patterns, identify clot risks and "see" brain, nervous and electrical functions during surgery. Other advances bridging nano and imaging technologies together could permit surgeons to visualize and operate at the cellular level. In general, with additional research, surgical tools will be smaller, less expensive, and easier to manipulate.

The field of image-guided interventions is at a critical juncture. The NIBIB leads the Interagency IGI Group, a trans-agency special interest group including representation from seven Federal agencies as well as 13 NIH Institutes and Centers. The need to support further research and development in IGI was documented at a January 2006 retreat of the Interagency IGI group. NIBIB-support has already led to major advances in this area and the Institute is poised to lead the technological advances that will revolutionize IGI in the future.

## IMAGING AT THE POINT OF PATIENT CARE

Medical imaging is critical for quality health care. Yet, sophisticated imaging services remain widely unavailable to many patients in small clinics and hospitals in rural and low-income communities. The development of low cost, portable imaging devices could extend point of care, modern diagnostic imaging techniques to millions of underserved Americans. Recent advances in miniaturization of electronic hardware and improved software may allow the development of widely available low-cost ultrasound devices to diagnose complications of pregnancy, hemorrhage associated with trauma, renal obstructions and other significant medical conditions. Similar advances in optical imaging may herald wider access to optical probes capable of early detection of cervical cancers. Additionally, advances in the electronic transmission of images can allow specialists located thousands of miles away to evaluate these point of care images and prescribe appropriate clinical treatment for millions of underserved patients.

Reduction of health disparities through new and affordable medical technologies is an explicit goal in NIBIB's Strategic Plan, and the Institute was established with this as one of its primary research initiatives. NIBIB has been a steady proponent of this research and recently launched a new initiative to develop low-cost imaging subsystems which attracted the attention of the Gates Foundation, as low-cost technologies are mutual priorities for both organizations. NIBIB is also spearheading the creation of a network of point-of-care research centers. Given NIBIB's strategic priority for developing low-cost imaging technologies, its leadership in this field, and its focus on point-of-patient-care technologies, NIBIB is ideally suited to lead a new major program to bring the benefits of advanced imaging technologies to all Americans.

## TISSUE ENGINEERING

The rapid development of transplant medicine along with the aging of the baby boomer generation have caused increased demand for tissues and organs far exceeding the available donor organs. As of May 2006, there were over 90,000 people on the waiting list for donor organs. Many of these individuals will die before a suitable organ can be found. By providing tissues and organs "on demand," regenerative medicine will improve the quality of life for individuals and reduce healthcare costs. A recent report by the Department of Health and Human Services (2020: A New Vision—A Future for Regenerative Medicine <http://www.hhs.gov/reference/newfuture.shtml>) underscores the need for a cohesive Federal initiative in this area. The NIBIB is poised to lead this initiative into the future.

Tissue Engineering is the cornerstone of regenerative medicine. It involves the growth and engineering of living, functional, tissues and organs. The long-range goal of tissue engineering is to use these tissues and organs to restore, maintain, or enhance function lost due to age, disease, damage or congenital defects. Tissue engineering has already seen some spectacular human successes, including nearly-complete regeneration of a severed finger and a functional bladder grown ex-vivo, as well as animal studies where motor function has been largely restored in a rat with a damaged spinal cord. Despite these successes, much still needs to be done to better understand why tissue regeneration starts and stops and to develop technologies to grow and preserve larger quantities of tissue.

Clearly tissue engineering is an emerging multidisciplinary field at the interface of the life and physical sciences. Thus, it is no surprise that NIBIB exerts a leadership role in the Multi-Agency Tissue Engineering working group for the President's National Science and Technology Council. Given its pivotal role in this area, NIBIB requires additional resources to fund the science necessary to accelerate advances in this critical area of biomedical science.

The current budget proposals for fiscal year 2008 do not measure up to the scientific opportunities in imaging. To be sure, these are stringent budgetary times. In such circumstances, the unique collaborative role of NIBIB offers the valuable potential for synergies with other NIH Institutes and other agencies of government that will stretch the value of scarce research dollars and expand the translational potential of the joint studies that are undertaken. Surely this is what Congress had in mind when it placed so much emphasis on breaking down the barriers separating the various Institutes, and disciplines at NIH. The NIBIB can only realize its vast collaborative and translational potential if it grows at a reasonable rate. As the newest of the NIH Institutes, it did not share in the doubling of the NIH budget that ended just as the new century began.

Failure to invest adequately in the NIBIB will have at least two negative consequences. First, scientific opportunities to improve diagnosis and treatment of a wide range of diseases will be, at best, delayed and could be lost. NIBIB Director

Rod Pettigrew has proposed a program of “quantum” projects designed to produce major breakthroughs in health care and medical science. Without additional resources, this initiative will surely be postponed or scaled back. Moreover, advanced research in other Institutes aimed at specific diseases will be set back by the delay in developing leading-edge imaging techniques that enable advanced research.

Second, it will discourage the large group of researchers who have been attracted to the NIH for the first time. Scientists in fields such as physics, mathematics, and computer science have been drawn to the NIBIB as a home for research that ties together the physical and biological sciences. Congress clearly sees such interdisciplinary research as the future of biomedical science, but that future could be delayed significantly if top scientists are discouraged from even submitting applications because funds are not available to support good research.

For these reasons, I hope that the committee will increase the 2008 appropriation for the NIBIB to \$350 million and consider a multi-year plan to build toward a budget that will enable the Institute to fulfill its collaborative mission.

The Congress created the NIBIB in 2000 to be different from the other Institutes. It is different because its primary mission is technology development. It is different because it does not focus on a single disease or organ system; instead, it is charged with developing new technologies with broad applications to many diseases and conditions. It is different because its foundation in the physical sciences separates it from the Institutes based on the biological sciences.

To a significant extent because of these differences, the NIBIB represents the future of interdisciplinary, team-driven biomedical science that is changing health care. I hope that the Congress will provide the resources needed to fulfill its promise.

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#### PREPARED STATEMENT OF THE AIDS ACTION COUNCIL

I am pleased to submit this testimony to the members of this committee on the importance of increased funding for the fiscal year 2008 HIV/AIDS portfolio. Since 1984, AIDS Action Council has worked to enhance HIV prevention programs, research protocols, and care and treatment services at the community, State, and Federal level. AIDS Action’s goals are to ensure effective, evidence-based HIV care, treatment, and prevention services; to encourage the continuing pursuit of a cure and a vaccine for HIV infection; and to support the development of a public health system which ensures that its services are available to all those in need. On behalf of AIDS Action Council’s diverse membership, comprising community-based HIV/AIDS service organizations, prevention services, public health departments, and education and training programs, I bring your attention to issues impacting funding for fiscal year 2008.

Despite the good news of improved treatments, which have made it possible for people with HIV disease to lead longer and healthier lives, stark realities remain:

- There are between 1.1 and 1.2 million people living with HIV in the United States.
- Half a million HIV positive people in the United States do not receive regular medical care including treatment for their disease.
- Between 200,000 and 300,000 people in the United States do not know that they are HIV positive.
- There are at least 40,000 preventable, new HIV infections each year. Approximately half of these infections occur in youth aged 13–24.
- Between 14,000–16,000 people die from HIV related causes each year.
- While African Americans comprise only 12 percent of the United States population, they account for approximately half (49 percent) of those infected with HIV/AIDS and 70 percent of new HIV infections each year.
- HIV was the #1 cause of death for Black women, aged 25–34, in 2004 the most recent year we for which have data.
- According to a CDC study released in 2005, 46 percent of urban African American men who have sex with men (MSM) were HIV-positive.
- 70 percent of HIV positive people depend on Federal programs to receive HIV treatment, care, and services.

The Federal Government’s commitment to funding research, prevention, and care and treatment for those living with HIV is critical. Despite this commitment, we are not doing enough. We need more prevention, more treatment and care and more research to slow and eventually reverse this epidemic.

AIDS Action Council concurs with many in the HIV community that increased support for HIV care and treatment, research, and prevention are critical. The community has come together under the umbrella of the AIDS Budget and Appropria-

tions Coalition with the community funding request for the HIV domestic portfolio for fiscal year 2008. The numbers requested represent that community work. These requests have been submitted to the committee.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, administered by the Health Resources and Services Administration (HRSA) and funded by this subcommittee, provides services to more than 533,000 people living with and affected by HIV throughout the United States and its territories. It is the single largest source of Federal funding solely focused on the delivery of HIV services. CARE Act programs have been critical to reducing the impact of the domestic HIV epidemic. Yet in recent years, CARE Act funding has decreased through across-the-board rescissions. The rescissions in fiscal year 2005 and fiscal year 2006 that were executed on all non-defense and non-homeland security discretionary spending during the final negotiations of the bills had a devastating impact on the HIV/AIDS portfolio in general, and on the Ryan White CARE Act in particular.

Now in its 17th year, the Ryan White CARE Act was reauthorized by the 109th Congress. The changes made by reauthorization, combined with the late enactment of fiscal year 2007 funding, has created the potential for crisis within the CARE Act. It is AIDS Action's hope that this subcommittee will recognize and address the true funding needs of the care programs within the domestic HIV/AIDS portfolio and make significant increases in all aspects of the HIV funding portfolio.

Five new jurisdictions were added to Ryan White CARE Act's Title I as transitional grant areas (TGAs), but no new funding was added for the Title I grantees in fiscal year 2007. Some of the services provided under Title I include physician visits, laboratory services, case management, home-based and hospice care, and substance abuse and mental health services. With the new reauthorization these services will be even more dedicated towards funding core medical services and to ensuring the ability of patients to adhere to treatment. These services are critical to ensuring patients have access to, and can effectively utilize, life-saving therapies. AIDS Action along with the HIV/AIDS community recommends funding Title I at \$840.4 million.

Title II of the CARE Act ensures a foundation for HIV related health care services in each State and territory, including the critically important AIDS Drug Assistance Program (ADAP) and Emerging Communities Program. Title II base grants (excluding ADAP and Emerging Communities) was the only program to receive an increase from \$331,000,000 in fiscal year 2006 to \$406,000,000 in fiscal year 2007 for a total increase of \$75,800,000. AIDS Action along with the HIV/AIDS community recommends funding for Title II base grants at \$463.4 million.

The AIDS Drug Assistance Program (ADAP) provides medications for the treatment of individuals with HIV who do not have access to Medicaid or other health insurance. According to the National ADAP Monitoring Project, approximately 96,404 clients received medications through ADAP in June 2005. The President recommends an increase of \$25.4 million for the critical AIDS Drug Assistance Program (ADAP) in his fiscal year 2008 budget. However this amount is far too low. AIDS Action along with the HIV/AIDS community recommends an increase of \$232.9 million for ADAP for fiscal year 2008. This request is derived from a pharmacoeconomic model to estimate the amount of funding needed to treat ADAP eligible individuals in upcoming Federal and State fiscal years.

Title III of the Ryan White CARE Act awards grants to community-based clinics and medical centers, hospitals, public health departments, and universities in 22 States and the District of Columbia under the Early Intervention Services program. These grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic in urban and rural settings. Title III funds are particularly needed in rural areas where the availability of HIV care and treatment is still relatively new. AIDS Action, along with the HIV/AIDS community, requests is an increase of \$87,800,000.

Title IV of the Ryan White CARE Act awards grants under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth, as well as their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families. AIDS Action and the HIV/AIDS community request is an increase of \$46,400,000.

Under Part F, the AIDS Education and Training Centers (AETCs) are the training arm of the Ryan White CARE Act; they train the healthcare providers, including the doctors, advanced practice nurses, physicians' assistants, nurses, oral health professionals, and pharmacists. The role of the AETCs is invaluable in ensuring that such education is available to healthcare providers who are being asked to treat the increasing numbers of HIV positive patients who depend on them for care. Additionally, the AETCs have been tasked with providing training on Hepatitis B

and C to CARE Act grantees and to ensure inclusion of culturally competent programs for and about HIV and Native Americans and Alaska Natives. However no funding was added for additional materials, training of staff, or programs. AIDS Action and the HIV/AIDS community request a \$15.3 million increase for this program.

Also under Part F, Dental care is another crucial part of the spectrum of services needed by people living with HIV disease. Unfortunately oral health is one of the first aspects of health care to be neglected by those who cannot afford, or do not have access to, proper medical care removing an opportunity to catch early infections of HIV. AIDS Action and the HIV/AIDS community request a \$5.9 million increase for this program.

AIDS Action and the HIV/AIDS community estimate that the entire Ryan White CARE Act portfolio needs \$2,794,300,000 for fiscal year 2008 to address the true needs of the over 1 million people that the Centers for Disease Control and Prevention (CDC) estimates are living with HIV in the United States. The fiscal year 2007 funding that was allocated was just over \$2 billion (\$2,112,000,000). This is a significant shortfall from the actual needs of people living with HIV.

The Minority AIDS Initiative directly benefits racial and ethnic minority communities with grants to provide technical assistance and infrastructure support and strengthen the capacity of minority community based organizations to deliver high-quality HIV health care and supportive services. HIV/AIDS in the United States continues to disproportionately affect communities of color. The Minority AIDS Initiative provides services across every service category in the CARE Act and was authorized for inclusion within the CARE Act for the first time in the 2006 CARE Act reauthorization. It additionally funds other programs throughout HHS. AIDS Action and the HIV/AIDS community request a total of \$610 million for the Minority AIDS Initiative.

The Housing Opportunities for People with AIDS (HOPWA) program, administered by the U.S. Department of Housing and Urban Development (HUD), is another integral program in the HIV care system. Stable housing is absolutely critical to the ability of people living with HIV to access and adhere to an effective HIV treatment plan. Stable housing plays a key role in HIV prevention; lack of housing is a known risk factor for HIV. Although HOPWA is not part of the Labor, Health and Human Services Appropriations bill, AIDS Action urges all Appropriations Committee members to support this critical program. AIDS Action requests that \$454,000,000 should be appropriated to the HOPWA program for fiscal year 2008.

According to CDC estimates contained in the agency's December 2005 HIV/AIDS Surveillance Report, 956,019 cumulative cases of AIDS have been diagnosed in the United States, with a total of 518,037 deaths since the beginning of the epidemic. As funding has remained essentially flat for more than 6 years, new infections also have stubbornly remained at the level of 40,000 per year. Dr. David Holtgrave, chair of the Johns Hopkins Bloomberg School Department of Health, Behavior and Society, has convincingly shown that there is a strong correlation between the lack of funding increases and the failure to reduce the number of new HIV infections. Therefore, AIDS Action Council estimates that the CDC HIV/AIDS, STD, and TB prevention programs will need \$1,597.3 million in fiscal year 2008 to address the true unmet needs of prevention in HIV/AIDS, STDs, and TB.

Research on preventing, treating and ultimately curing HIV is vital to the domestic control of the disease. The United States must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. Primary prevention of new HIV infections must remain a high priority in the field of research. It is essential that NIH continues its groundbreaking research to secure a prevention vaccine and continue to research promising treatment vaccines that may help HIV positive people maintain optimal health. Research on microbicides [gels, creams or other substances that prevent the sexual transmission of HIV and other sexually transmitted infections (STIs) when applied topically] for vaginal and anal sexual intercourse is also critical. Continued research on new medications for drug resistant strains of HIV is also critical. Finally, behavioral research to increase knowledge of sexual behavior and research to help individuals delay the initiation of sexual relations, limit the number of sexual partners, limit high-risk behaviors related to alcohol and substance use and move from drug use to drug treatment are all critically important. NIH's Office of AIDS Research is critical in supporting all of these research arenas. AIDS Action requests that the National Institutes of Health AIDS portfolio be funded at \$3.2 billion for fiscal year 2008 an increase of \$300 million over fiscal year 2007.

HIV is a continuing health crisis in the United States. On behalf of all HIV positive Americans, and those affected by the disease, AIDS Action Council urges you to increase funding in each of these areas of the domestic HIV/AIDS portfolio. Help

us save lives by allocating increased funds to address the HIV epidemic in the United States.

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PREPARED STATEMENT OF THE ALPHA-1 FOUNDATION

Agency Recommendations:

1. NIH: The Alpha-1 Foundation requests an allocation in the budget to enable the NIH, NHLBI to focus additional research leading to a better understanding of Alpha-1, including improved management and therapeutic approaches. The Foundation observes that much can be learned by studying the biology of Alpha-1, a human model of environment-gene interaction, which will inform Chronic Obstructive Pulmonary Disease (COPD) and liver cirrhosis, both of which are major public health concerns. The Foundation requests cooperation between NHLBI, NIDDK, NHGRI, and other institutes to enhance targeted detection, raise public awareness about Alpha-1 and provide appropriate information to health professionals. The Foundation recommends achieving these goals through use of the NHLBI Rare Lung Diseases Consortium and the COPD Clinical Research Network.

2. NIH: The Foundation commends NHLBI for their national launch of the COPD Awareness and Education Campaign titled "COPD Learn More Breathe Better" and recommends that NHLBI continue to enhance its portfolio of research and education on the fourth leading cause of death in the United States, Chronic Obstructive Pulmonary Disease (COPD), including genetic risk factors such as Alpha-1 Antitrypsin Deficiency.

3. NIH: The Alpha-1 Foundation notes that the severe adult-onset lung disease caused by Alpha-1 stems directly from the protein secretion abnormality in the livers and lungs of affected individuals. Alpha-1 has also been shown to be a risk factor for hepatitis C and B infection. The Foundation requests that NIDDK collaborate with NHLBI, NCI and other institutes to enhance its research portfolio, encourage detection, raise public awareness and provide appropriate information to health professionals. The Foundation encourages the use of the NIDDK Cholestatic Liver Disease Consortium to achieve these goals.

4. NIH: The Foundation notes that given the link between environmental factors and the onset of Alpha-1 related COPD, the committee encourages NIEHS to develop research initiatives to explore gene environment interaction research and develop support for public private partnerships.

5. CDC: The Foundation requests that CDC develop a program to promote early detection of Alpha-1 so that individuals can engage in preventative health measures and receive appropriate therapies which significantly improve their health status. The Foundation requests a public private partnership to actively support Alpha-1 targeted detection efforts that utilize public and professional education regarding chronic obstructive lung disease, both genetic and tobacco related.

DISCLOSURE

Title: Rare Lung Disease Clinical Research Network Grant #1 U54 RR019498-01  
Principal Investigator: Bruce C. Trapnell, M.D., University of Cincinnati Medical School

Dates: 09/01/03 through 08/31/08

Total Costs—\$5,520,790

The Foundation receives a small percentage of this grant as the coordinating center.

Thank you for the opportunity to submit testimony for the record on behalf of the Alpha-1 Foundation.

THE ALPHA-1 FOUNDATION

The Alpha-1 Foundation is a national not-for-profit organization dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1 Antitrypsin (Alpha-1) Deficiency. The Foundation has built the research infrastructure with private investment, funding over \$28,000,000 in grants from basic to social science, establishing a national patient registry, tissue and Biobank, translational laboratory, assisting in fast track development of new therapeutics, and stimulating the involvement of the scientific community. The Foundation has invested the resources to support clinical research uniquely positioning ourselves for a perfect private public partnership. There is a lack of awareness of the insidious nature of the early symptoms of the lung and liver disease associated with this genetic condition by both medical care providers

and the public. It is our hope that the Federal Government will leverage the Foundation's investment with support for a national Alpha-1 targeted detection program.

#### ALPHA-1 IS SERIOUS AND LIFE THREATENING

Alpha-1 is the leading genetic risk factor for Chronic Obstructive Pulmonary Disease (COPD) and is often misdiagnosed as such. Alpha-1 afflicts an estimated 100,000 individuals in the United States with fewer than 5 percent accurately diagnosed. These are people who know they are sick and as yet have not put a name to their malady. Although Alpha-1 testing is recommended for those with COPD this standard of care is not being implemented. In addition, an estimated 20 million Americans are the undetected carriers of the Alpha-1 gene and may pass the gene on to their children. Of these 20 million carriers, 7–8 million may be at risk for lung or liver disease.

The pulmonary impairment of Alpha-1 causes disability and loss of employment during the prime of life (20–40 years old), frequent hospitalizations, family disorganization, and the suffering known only to those unable to catch their breath. Fully half of those diagnosed require supplemental oxygen. Lung transplantation, with all its associated risks and costs, is the most common final option. Alpha-1 is the primary cause of liver transplantation in infants and an increasing cause in adults. Alpha-1 liver disease currently has no specific treatment aside from transplantation. The cost to these families in time, energy and money is high and often devastating. Alpha-1 also causes liver cancer.

Alpha-1 is a progressive and devastating disorder that in the absence of proper diagnosis and therapy leads to premature death; in spite of the availability of therapeutics for lung disease and preventative health measures that can be life-prolonging. It is estimated that untreated individuals can have their life expectancy foreshortened by 20 or more years. Yet early detection, the avoidance of environmental risk factors and pulmonary rehabilitation can significantly improve health.

#### ALPHA-1 AND COPD

As the forth leading cause of death, COPD is a major public health concern. Data indicates that not all individuals who smoke develop lung disease leading many to conclude that COPD has significant genetic and environmental risk factors. As the most significant genetic risk factor for COPD, Alpha-1 has much to tell us about the pathogenesis of lung disease. Discoveries and advances made in Alpha-1 will impact the larger 12–24 million individuals living with COPD.

#### DETECTION

The Alpha-1 Foundation conducted a pilot program in the State of Florida where we garnered the knowledge and experience necessary to launch an awareness and National Targeted Detection Program (NTDP). The goals of the NTDP are to educate the medical community and people with COPD and liver disease, alerting them that Alpha-1 may be an underlying factor of their disease; and stimulating testing for Alpha-1. This effort will uncover a significant number of people who would benefit from early diagnosis, treatment and preventative health measures.

The Foundation distributes the American Thoracic Society/European Respiratory Society (ATS/ERS) "Standards for the Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency" to physicians, nurses and respiratory therapists. Additionally, health care practitioners and the COPD community are being targeted through press releases, newsletter articles and various website postings.

The national implementation of the NTDP is enhanced through the 7 Clinical Resource Network Centers of the National Heart, Lung, Blood Institute of the National Institutes of Health; 51 Foundation affiliated Clinical Resource Centers; large pulmonary practices and various teaching hospitals and universities. The NTDP also employs a direct to consumer approach targeted to people with COPD.

The Alpha-1 Foundation's Ethical Legal and Social Issues (ELSI) Working Group endorsed the recommendations of the ATS/ERS Standards Document which recommends testing symptomatic individuals or siblings of those who are diagnosed with Alpha-1. Early diagnosis in Alpha-1 can significantly impact disease outcomes by allowing individuals to seek appropriate therapies, and engage in essential life planning. Unfortunately, seeking a genetic test may lead to discrimination against individuals who have no control over their inherited condition. The absence of Federal protective legislation has caused the ELSI to recommend against population screening and genetic testing in the neonatal population. The Foundation is encouraged that the House has passed the Genetic Information Nondiscrimination Act of 2007 out of committee and may soon take this measure up on the House floor.

The Alpha-1 Coded Testing (ACT) Trial, funded by the Alpha-1 Foundation and conducted at the Medical University of South Carolina offers a free and confidential finger-stick test that can be completed at home. The results are mailed directly to the participants. The ACT Trial has offered individuals the opportunity to receive confidential test results since September 2001.

#### ALPHA-1 RESEARCH

The Alpha-1 Foundation believes that significant Federal investment in medical research is critical to improving the health of the American people and specifically those affected with Alpha-1. The support of this subcommittee has made a substantial difference in improving the public's health and well-being.

The Foundation requests that the National Institutes of Health increase the investment in Alpha-1 Antitrypsin (AAT) Deficiency and that the Centers for Disease Control and Prevention initiate a Federal partnership with the Alpha-1 community to achieve the following goals:

- Promotion of basic science and clinical research related to the AAT protein and AAT Deficiency;
- Funding to attract and train the best young clinicians for the care of individuals with AAT Deficiency;
- Support for outstanding established scientists to work on problems within the field of AAT research;
- Development of effective therapies for the clinical manifestations of AAT Deficiency;
- Expansion of awareness and targeted detection to promote early diagnosis and treatment.

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#### PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

Chairman Harkin, ranking member Specter and members of the subcommittee, thank you for the opportunity to submit testimony regarding funding for key programs that address the enormous demographic and economic impact that Alzheimer's disease presents to our society.

Last month, the Alzheimer's Association released a comprehensive report indicating that Alzheimer's is much more pervasive than we thought. The report confirms that more than 5 million people in the United States are living with Alzheimer's disease today, including 200,000 or more under the age of 65. This is a 10 percent increase from previous estimates, but it is only the tip of the iceberg. By mid-century, as many as 16 million Americans will have the disease. We will see half a million new cases of Alzheimer's this year alone. That means someone in America is developing Alzheimer's disease every 72 seconds!

The report also sheds new light on dramatic shift in mortality among Americans. A diagnosis of Alzheimer's is a death sentence and death rates for Alzheimer's are rising dramatically, up nearly 33 percent in just 4 years while other leading causes of death—heart disease, stroke, breast and prostate cancer—are declining. Alzheimer's is the seventh leading cause of death for people of all ages and the fifth leading cause of death for people age 65 and older. The absence of effective disease modifying drugs, coupled with the aging of the baby boomers, makes Alzheimer's the health care crisis of the 21st century.

Alzheimer's already costs the Nation \$148 billion a year. Medicare alone spent \$91 billion on beneficiaries with the disease in 2005 and Medicaid spent another \$21 billion. By 2015 those two programs will be spending more than \$210 billion just on people with Alzheimer's. The disease is also overwhelming health and long term care systems: 25 percent of elderly hospital patients, 47 percent of nursing home residents, and at least 50 percent of people in assisted living and adult day care have Alzheimer's or another dementia.

The impact of Alzheimer's on American families is just as devastating. Today at least 10 million family members provide unpaid care. In Iowa, these caregivers are providing nearly 81 million hours of care a year; in Pennsylvania, almost 375 million hours. Nationwide, the work Alzheimer caregivers are doing is valued at nearly \$83 billion and consumes 8.5 billion hours annually.

Alzheimer's disease is exploding into an epidemic that will undermine all of our best efforts to control health care costs, assure access to quality care, and protect the retirement security of generations to come. This is the reality of Alzheimer's disease. It is not a pretty picture. But it is a picture that we can change. Today, there is real hope that we can get Alzheimer's under control, that we will find the ways to prevent millions from ever getting the disease, and that for those who do get it; we can change it from a death sentence to a manageable chronic illness.

Today, the Alzheimer research community can report genuine, tangible, quantifiable hope for effective prevention and treatment of Alzheimer's disease. Within the next 3 years, it is very likely that we will have disease-modifying drugs that could fundamentally change the nature of Alzheimer's. If we succeed, for millions of Americans, a diagnosis of Alzheimer's disease will no longer be a death sentence but the beginning of a manageable chronic illness.

The drugs being tested are very different from the ones now on the market. Current drugs treat the symptoms of Alzheimer's but leave the underlying disease untouched. While they do help some patients temporarily, the predictable progression to death continues along the cruel path we know too well. The new drugs are designed to attack the disease directly. Results to date are very encouraging. These drugs are safe. Patients tolerate them well. And they appear to show significant positive impact, slowing the progression of the disease. Higher doses or combination drugs might arrest the process completely. One of the drugs currently in clinical trials could go to the Food and Drug Administration for review as early as this fall.

The other exciting news is that scientists are rapidly gaining knowledge about genetic and other risk factors of Alzheimer's disease, and developing techniques to detect early changes in the brain well before symptoms appear. These discoveries will let the medical community identify persons at risk of Alzheimer's, diagnose pre-symptomatic disease, and begin treatment in time to prevent development of dementia altogether.

All of this good news is the direct result of your decision to double funding for the National Institutes of Health. The influx of resources moved Alzheimer research from a backwater of obscurity to perhaps the single most visible, most competitive, and most exciting field in the neurosciences. This is the key to drug discovery. Drug development does not start or end with pharmaceutical companies. It begins at NIH-funded laboratories at academic health centers, where scientists uncover the molecular basis of disease, identify treatment strategies, and develop the research methods and techniques that make clinical investigation possible. Clinical trials depend on the expertise of NIH-funded investigators, and many require direct NIH funding because the drugs under investigation are not protected by patent.

The emphasis on the fundamental role of NIH funding is critical because there is still so much work to be done. We are right to be excited about treatments that attack the amyloid plaques, one of the primary hallmarks of Alzheimer's disease. But they will not likely be the complete answer. Like cancer and heart disease, Alzheimer's is a complex puzzle. Solving it will involve multiple strategies. There are already a number of other potential targets for intervention—including the chemical basis of the tangles in the brain that are the other hallmark of Alzheimer's, the relationship between heart and vascular disease and Alzheimer's, the connection to Type 2 diabetes, the role of nerve growth factors, and the interaction of environment, life style choices, and genetics in the development of disease.

If science can validate the prevailing wisdom about amyloid, and if researchers can refine these other theories, then every major pharmaceutical company will begin bringing new drugs into human clinical trials. That will not happen, however, unless Congress provides the funds to sustain the Alzheimer research enterprise. Despite its devastating consequences, research on Alzheimer's disease remains seriously under-funded.

In 2003, annual NIH funding of Alzheimer research peaked at \$658 million. The scientific community is living off the results of that investment, but we now risk losing that momentum. Since 2003, there has been a slow, steady decline in funding—down to \$643 million this year and even less if Congress approves the President's fiscal 2008 budget request. In constant dollars, the drop is devastating—a 14 percent decline in overall funding at the National Institute on Aging (NIA) alone.

This is happening at a time when the scientific opportunities have never been greater. There are more highly promising avenues of inquiry to explore than ever before. And researchers now have research tools at their disposal, involving genetics and imaging, that can help get better, quicker answers. But scientists cannot use those tools without adding funds to existing projects.

The slow down in funding is already having an impact in the Alzheimer research community. NIA is funding less than 18 percent of the most highly rated investigator-initiated projects it receives—down from a 30 percent success rate in 2003. What is more, the first-year grants that are awarded are funded at 18 percent below the level recommended by NIA's own independent review panels. There are no inflationary adjustments in the out-years or for existing projects. This means that most scientific opportunities are left on the table, and the successful ones are being seriously under-funded. It also means that some of the most promising clinical trials—the way to translate basic research findings into effective treatments—will be delayed or scrapped altogether. Conversations within the Alzheimer research commu-

nity confirm that we are at risk of losing a generation of scientists, young investigators who are either choosing less traditional careers or are leaving research altogether. These brilliant minds are our greatest resource, and we should be applying them to our most difficult problems. Only money will bring them back.

These budget cuts are not just killing research projects. They are killing the minds of millions of Americans. And they are killing our chances of getting health care spending under control. If we let the disease continue on its current trajectory, in less than 25 years Medicare will be spending almost \$400 billion on 10 percent of its beneficiaries—those with Alzheimer's. That is almost as much as we are spending in the entire Medicare program for all beneficiaries today.

We can cut that spending dramatically—saving over \$50 billion annually—within just 5 years of even modest breakthroughs that would delay the onset of Alzheimer's and slow its progression. And we can also save millions of families from devastation. Within 20 years of a breakthrough, there would be 3.7 million fewer cases of Alzheimer's in the United States than there are today—in spite of the rapid aging of the baby boomers. And among those who would still develop the disease, most would never progress beyond the mild stages of the disease and could continue to live productively with their families in the community.

We cannot win this fight against Alzheimer's without an all-out commitment from Congress and from every relevant part of the Federal Government—especially NIH and the Food and Drug Administration (FDA). The Alzheimer's Association is working closely with all these agencies to maximize our mutual efforts within the limits imposed by existing law and resources. We are proud of our longstanding partnership with the National Institute on Aging and the tremendous commitment of Dr. Richard Hodes and his dedicated staff. We are also gratified by the response of the Food and Drug Administration to our Effective Treatments Initiative, to increase its focus on Alzheimer's and to bring patients and caregivers into the drug review process.

Mr. Chairman and subcommittee members—we are in a race against time. With every year that passes, we risk losing that race. The Alzheimer's Association respectfully requests that you provide sufficient resources for NIH in the fiscal year 2008 Labor/HHS/Education Appropriations bill so that funding for Alzheimer research can be increased by \$125 million. The Association also seeks continued support for proven programs that are serving hundreds of thousands of Alzheimer families, including \$1 million for the 24/7 Alzheimer's Call Center and \$12 million for the Alzheimer's Disease Matching Grants to States Program administered by the Administration on Aging. Services provided by the Call Center include access to professional clinicians who provide decision-making support, crisis assistance and education on issues caregivers face every day. The Call Center also provides referrals to local community programs and services. The Alzheimer's Disease Matching Grants to States Program provides funds to States for the development of innovative and cost effective programs that influence broader healthcare systems and provide community-based services for those with Alzheimer's and their caregivers. The program has a special emphasis on reaching hard-to-reach and underserved people such as minorities, low income persons, and those living in rural/frontier communities. 38 States, including Iowa, are currently participating in the program.

In addition, we urge you to increase funding for the Centers for Disease Control & Prevention (CDC) Brain Health Initiative to \$3 million. Since fiscal year 2005, Congress has provided approximately \$1.6 million annually to the CDC to develop and implement the first single-focused effort on brain health promotion. As a result of this initial support, the CDC and the Alzheimer's Association have begun collaborating on a multi-faceted approach to brain health that includes both programmatic and public health research components. This Initiative is currently focused on four primary activities: development of a Roadmap to Maintaining Cognitive Health, implementation of community demonstration programs, creation of communication linkages with the public, and elevation of brain health research. Increasing support for this Initiative to \$3 million would allow for broader dissemination of the Roadmap to Maintaining Cognitive Health, provide funds to expand the community demonstration projects to other high risk, underserved populations, specifically the Hispanic/Latino population and support the development of a strategic initiative for early detection and secondary prevention of Alzheimer's disease, including consideration of appropriate screening/diagnostic tools, needed education strategies, and appropriate follow up to diagnosis.

We urge Congress to add the funding we need to break through the finish line ahead of the baby boomers who are nipping at our heels. The funding for Alzheimer research and care programs that we seek requires a modest investment in total Federal budget terms but it has the potential for enormous returns—in reduced health

and long-term care costs to Federal and State budgets and in improved quality of life for millions of American families.

Thank you again for the opportunity to submit this testimony for the record.

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#### PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 93,800 members of the American Academy of Family Physicians are grateful for this opportunity to submit for the record our recommendations for Federal fiscal year 2008 to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education.

The American Academy of Family Physicians (AAFP) is one of the largest national medical organizations, representing family physicians, family medicine residents, and medical students nationwide. Founded in 1947, our mission has been to preserve and promote the science and art of family medicine and to ensure high-quality, cost-effective health care for patients of all ages. We believe that Federal spending policy can help to transform health care to achieve optimal health for everyone.

We recommend that, as an essential part of that policy, the fiscal year 2008 Appropriations bill to fund the Departments of Labor, Health and Human Services and Education should restore funding for health professions training programs, increase our investment in the Agency for Healthcare Research and Quality and continue support for rural health programs.

#### HEALTH RESOURCES & SERVICES ADMINISTRATION—HEALTH PROFESSIONS

For the last 40 years, the health professions training programs authorized under Title VII of the Public Health Services Act have evolved in order to meet our Nation's changing health care workforce needs.

Section 747 of Title VII, the Primary Care Medicine and Dentistry Cluster, is aimed at increasing the number of primary care physicians (family physicians, general internists and pediatricians) as well as the number of highly-skilled health care professionals to provide care to the underserved. Section 747 offers competitive grants for family medicine training programs in medical schools and in residency programs.

The value of these grants extends far beyond the medical schools that receive them. The United States lags behind other countries in its focus on primary care. However, the evidence shows that countries with primary care-based health systems have population health outcomes that are better than those of the United States at lower costs.<sup>1</sup> Health Professions Grants are one important tool to help refocus this Nation's health system on primary care.

#### *Disease Prevention*

First of all, Federal support of Title VII, section 747 for primary care training is critical to increase the number of family physicians whose specialty emphasizes a broad range of skills in caring for the whole patient regardless of age, gender or medical condition. Primary care provided by family physicians looks to a patient's total health needs and is strongly oriented toward preventing illness and injury.

#### *Chronic Care Management*

Second, primary care is ideally suited to managing chronic disease. Regrettably, nearly one in five Americans lacks access to primary medical care for regular and on-going care. A recent study "found 56 million Americans of all income levels, race and ethnicity, and insurance status have inadequate access to a primary care physician due to shortages of these physicians in their communities."<sup>2</sup>

#### *Lower Costs*

Americans with a "medical home" to provide primary care for such basic needs as treating ear infections, controlling high blood pressure, or managing diabetes have better health outcomes at a lower cost of care.<sup>3</sup> Without adequate numbers and distribution of primary care physicians, we cannot provide the quality of preventive care designed to avoid costlier services in hospital emergency departments.

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<sup>1</sup>Starfield B, et al. The effects of specialist supply on populations' health: assessing the evidence. Health Affairs. 15 March 2005.

<sup>2</sup>National Association of Community Health Centers, The Robert Graham Center. Access Denied: A Look at America's Medically Disenfranchised. March 2007.

<sup>3</sup>Ibid.

### *Primary Care Physician Shortages*

Support for family medicine training programs is needed to address insufficient access to primary care services which is caused by both an overall shortage and an uneven distribution of physicians. Family medicine is a critical part of the solution to providing high-quality, affordable and accessible health care to everyone.

On March 15, 2007, the annual National Resident Matching Program announced results showing the number of medical students choosing careers in family medicine remains stagnant, raising concerns the primary care physician workforce will not be adequate to meet the needs of an aging population with an increased prevalence of chronic disease.

The AAFP's 2006 Family Physician Workforce Reform report called for a workforce of 139,531 family physicians, or a ratio of 41.6 family physicians per 100,000 U.S. population by 2020. To meet that demand, our medical education system must produce 4,439 new family physicians annually.

In the 2007 National Resident Matching Program 2,313 applicants matched to family medicine residency positions compared with 2,318 in 2006. Also down was the total number and percentage of U.S. students who match to family medicine: 1,107 or 7.8 percent of participating U.S. graduates matched to family medicine this year, compared to 1,132 or 8.1 percent in 2006. This year, there were 106 fewer family medicine residency positions offered than in 2006.

Last fall, the AAFP Congress of Delegates, in recognition of the need for more family physicians to meet the escalating health care needs of the American people, called for preferential funding for section 747 as well as those training programs that produce physicians from underrepresented minorities, or those whose graduates practice in underserved communities or serve rural and inner-city populations.

In opposition to funding for Health Professions Grants, the administration cited an Office of Management and Budget 2002 Program Assessment Rating Tool (PART) assessment of Title VII that called the program ineffective. In fact, data show that medical schools and primary care residency programs funded by Title VII section 747 do disproportionately serve as the medical education pipeline that produces physicians who go on to work in Community Health Centers and participate in the National Health Service Corps to treat underserved populations.<sup>4</sup>

In order to achieve a valid OMB PART analysis, the Health Professions program must be given clear goals and objectives. The Advisory Committee on Training in Primary Care Medicine and Dentistry called for by the Health Professions Education Partnership Act of 1998 has proposed steps to clarify, in the authorizing law, the purpose and objectives of Title VII, section 747. AAFP is working with the authorizing committees to ensure that the reauthorization addresses these recommendations.

Although the Title VII programs intended to support the preparation of an effective, diverse primary care workforce have been repeatedly targeted for elimination in Presidential budget requests, the committee has provided appropriations for these important accounts. The final spending resolution for fiscal year 2007 provided \$184.75 million, a 27.2 percent increase above the fiscal year 2006 level for all of Title VII. The Primary Medicine and Dentistry Cluster, section 747, received an increase of 19.6 percent from the fiscal year 2006 level to \$48.85 million. However, this level falls far short of the appropriation of \$92 million provided in fiscal year 2003.

The AAFP is committed to a high level of support for education in family medicine residency programs and family medicine departments and divisions in medical schools.

We hope that the committee will make an adequate investment in a well-prepared primary care workforce in order to provide improved health care at a reduced cost.

AAFP recommends an increase in the fiscal year 2008 appropriation bill for the Health Professions Training Programs authorized under Title VII of the Public Health Services Act. We respectfully suggest that the committee provide at least \$300 million for Title VII, including \$92 million for the section 747, the Primary Care Medicine and Dentistry Cluster, which will restore this vital program to its fiscal year 2003 level.

### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of health care for all Americans—closely mirrors AAFP's own mission. AHRQ has a unique responsibility for

<sup>4</sup>University of California, San Francisco.

research to inform decision-making and improve clinical care. In addition to AHRQ's charge to evaluate health care practice cost-effectiveness, the agency is engaged in the effort to advance personalized health care with the Health Information Technology Initiative.

#### *Health Information Technology*

The initial work by AHRQ to facilitate the adoption of health information technology is important to improve patient safety by reducing medical errors and to avoid costly duplication of services. AAFP recognizes that health information technology, used effectively, can transform health care. It is vital that AHRQ, as the lead Federal agency, have the necessary resources to promote standards for portability and interoperability which ensure that health data is appropriately available and privacy protected.

#### *Comparative Clinical Effectiveness Research*

According to the Centers for Medicare and Medicaid Services' National Health Statistics Group, health care spending will double to \$4.1 trillion and account for 20 percent of every dollar spent by 2016. Our Nation must invest in the study of health care practice in order to improve outcomes and minimize unnecessary costs. One important tool to accomplish this is AHRQ's analysis of clinical effectiveness and appropriateness of health services and treatments. This practical research will improve Federal programs such as Medicare, Medicaid and SCHIP as well as privately-financed health care.

AAFP recommends an increase in the fiscal year 2008 appropriation bill for the Agency for Healthcare Research and Quality (AHRQ). We respectfully suggest that the committee provide at least \$350 million for AHRQ, an increase of \$31 million above the fiscal year 2007 level.

#### RURAL HEALTH PROGRAMS

Family physicians provide the majority of care for America's underserved and rural populations.<sup>5</sup> Despite efforts to meet shortages in rural areas, there continues to be a shortage of physicians. Studies, whether they be based on the demand to hire physicians by hospitals and physician groups or based on the number of individuals per physician in a rural area, all indicate a need for additional physicians in rural areas. Continued funding for rural programs is vital to provide adequate health care services to America's rural citizens. We support the Federal Office of Rural Health Policy; Area Health Education Centers; the Community and Migrant Health Center Program; and the NHSC. State rural health offices, funded through the National Health Services Corps budget, help States implement these programs so that rural residents benefit as much as urban patients.

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#### PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

This statement is endorsed by: Ambulatory Pediatric Association and Society for Adolescent Medicine.

There can be no denying that there have been numerous and significant successes in improving the health and well-being of America's children and adolescents, from even just decades ago. Infant and child mortality rates have been radically lowered. The number of 2-year-olds who have received the recommended series of immunizations is at an all-time high, while vaccine-preventable diseases such as measles, pertussis, and diphtheria have decreased by over 98 percent. Teen pregnancy rates have declined by 28 percent over the last decade. Still, despite these successes, far too many children and adolescents in America continue to suffer from disease, injury, abuse, racial and ethnic health disparities, or lack of access to quality care. In addition, more than 9 million children and adolescents through the age 18 remain uninsured. Clearly there remains much work to do.

As clinicians we not only diagnose and treat our patients, we must also promote strong preventive interventions to improve the overall health and well-being of all infants, children, adolescents and young adults. The AAP, SAM and APA have identified three key priorities within this committee's jurisdiction that are at the heart of improving the health and well-being of America's children and adolescents: access to health care, quality of health care, and immunizations. A chart at the end of this

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<sup>5</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Division of Data Services. National ambulatory medical care survey.

statement will offer funding recommendations for other programs of importance to the child and adolescent community.

#### ACCESS

We believe that all children, adolescents and young adults should have full access to comprehensive, age-appropriate, quality health care. From the ability to receive primary care from a pediatrician trained in the unique needs of children and adolescents, to timely access, to pediatric medical subspecialists and pediatric surgical specialists, America's children and adolescents deserve access to quality pediatric care in a medical home. Given the recent cuts to the Medicaid program and fiscal belt-tightening in the States, discretionary programs now more than ever provide a vital health care safety net for America's most vulnerable children and youth.

*Maternal and Child Health Block Grant.*—The Maternal and Child Health (MCH) Block Grant Program at the Health Resources and Services Administration (HRSA) is the only Federal program exclusively dedicated to improving the health of all mothers and children. Nationwide, the MCH Block Grant Program provides preventive and primary care services to over 32 million women, infants, children, adolescents and children with special health care needs. In addition, the MCH Block Grant Program supports community programs around the country in their efforts to reduce infant mortality, prevent injury and violence, expand access to oral health care, and address racial and ethnic health disparities. Moreover, the MCH Block Grant Program includes efforts dedicated to addressing interdisciplinary training, services and research for adolescents' physical and mental health care needs, and supports programs for vulnerable adolescent populations, including health care initiatives for incarcerated and minority adolescents, and violence and suicide prevention. It also plays an important role in the implementation of the State Children's Health Insurance Program (SCHIP). One of the many successful MCH Block Grant programs is the Healthy Tomorrows Partnership for Children Program, a public/private collaboration between the MCH Bureau and the American Academy of Pediatrics. Established in 1989, Healthy Tomorrows has supported over 150 family-centered, community-based initiatives in almost all States, including Ohio, Wisconsin, New York, California, Rhode Island, and Maryland. These initiatives have addressed issues such as access to oral and mental health care, obesity, injury prevention, and enhanced clinical services for chronic conditions such as asthma. To continue to foster these and other community-based solutions for local health problems, in fiscal year 2008 we strongly support an increase in funding for the MCH Block Grant Program to \$750 million.

*Family Planning Services.*—The family planning program, Title X of the Public Health Services Act, ensures that all teens have confidential access to valuable family planning resources. For every dollar spent on family planning through Title X, \$3 is saved in pregnancy-related and newborn care costs to Medicaid. Title X—which does not provide funding for abortion services—provides critically needed preventive care services like pap tests, breast exams, and STI tests to millions of adolescents and women. But over 9.5 million cases of sexually transmitted infection (STIs) (almost half the total number) are in 15–24 year olds, and over 30 percent of women will become pregnant at least once before age 20. Teen pregnancy rates continue to vary between racial and ethnic groups, and nearly half (48 percent) of all teens say that they want more information from—and increased access to—sexual health care services. Responsible sexual decision-making, beginning with abstinence, is the surest way to protect against sexually transmitted infections and pregnancy. However, for adolescent patients who are already sexually active, confidential contraceptive services, screening and prevention strategies should be available. We therefore support a funding level in fiscal year 2008 of \$385 million for Title X of the Public Health Service Act.

*Mental Health.*—It is estimated that over 13 million children and adolescents have a mental health problem such as depression, ADHD, or an eating disorder, and for as many as 6 million this problem may be significant enough to impact school attendance, interrupt social interactions, and disrupt family life. Despite these statistics, the National Institute of Mental Health (NIMH) estimates that 75–80 percent of these children fail to receive mental health specialty services, due to stigma and the lack of affordability of care and availability of specialists. Grants through the Children's Mental Health Services program have been instrumental in achieving decreased utilization of inpatient services, improvement in school attendance and lower law enforcement contact for children and adolescents. We recommend that \$112 million be allocated in fiscal year 2008 for the Mental Health Services for Children program to continue these improvements for children and adolescents with mental health problems.

*Child Abuse and Neglect.*—Recent research from the CDC’s Adverse Childhood Experiences study and others demonstrates that childhood trauma may contribute significantly to the development of numerous adult health conditions, including alcoholism, drug abuse, heart disease and more. However, few Federal resources are dedicated to bringing the medical profession into full partnership with law enforcement, the judiciary, and social workers, in preventing, detecting, and treating child abuse and neglect. We urge the subcommittee to provide an increase of \$10 million in fiscal year 2008 for the Center for Disease Control and Prevention’s National Center for Injury Prevention and Control to establish a network of consortia to link and leverage health care professionals and resources to address—and ultimately prevent—child maltreatment. We also support the recommendation of the National Child Abuse Coalition to fund the Child Abuse Prevention and Treatment Act program at \$200 million.

*Health Professions Education and Training.*—Critical to building a pediatric workforce to care for tomorrow’s children and adolescents are the Training Grants in Primary Care Medicine and Dentistry, found in Title VII of the Public Health Service Act. These grants are the only Federal support targeted to the training of primary care professionals. They provide funding for innovative pediatric residency training, faculty development and post-doctoral programs throughout the country. For example, a pediatrician in New Jersey stated the following: “Reduction in Title VII funding would negatively impact all areas of our current activities, including recruitment of under-represented minority trainees and faculty, cultural competency initiatives, clinical experiences for aspiring health professionals and patient care for thousands of underserved urban infants, children and adolescents.”

Through the continuing efforts of this subcommittee, Title VII has provided a vital source of funding for critically important programs that educate and train tomorrow’s generalist pediatricians in a variety of settings to be culturally competent and to meet the special health care needs of their communities. We recommend fiscal year 2008 funding of at least \$40 million for General Internal Medicine/General Pediatrics. We also join with the Health Professions and Nursing Education Coalition in supporting an appropriation of at least \$550 million in total funding for Titles VII and VIII. We support the administration’s increase in funding for Community Health Centers, a key component with Title VII to ensuring an adequate distribution of health care providers across the country; but we emphasize the need for continued support of the training and education opportunities through Title VII for health care professionals, including pediatricians, who provide care for our Nation’s communities.

*Independent Children’s Teaching Hospitals.*—Equally important to the future of pediatric education and research is the dilemma faced by independent children’s teaching hospitals. In addition to providing critical care to the Nation’s children, independent children’s hospitals play a significant role in training tomorrow’s pediatricians and pediatric subspecialists. Children’s hospitals train 30 percent of all pediatricians, half of all pediatric subspecialists, and the majority of pediatric researchers. However, children’s hospitals qualify for very limited Medicare support, the primary source of funding for graduate medical education in other inpatient environments. As a bipartisan Congress has recognized in the last several years, equitable funding for Children’s Hospitals Graduate Medical Education (CHGME) is needed to continue the education and research programs in these child- and adolescent-centered settings. Since 2000, CHGME hospitals accounted for nearly 87 percent of the growth in pediatric subspecialty training programs and 68 percent of the growth in pediatric subspecialty fellows trained. We are extremely disappointed in the 63 percent reduction in funding proposed by the administration for the CHGME program, and join with the National Association of Children’s Hospitals to restore funding to \$330 million for the CHGME program in fiscal year 2007. The support for independent children’s hospitals should not come, however, at the expense of valuable Title VII and VIII programs, including grant support for primary care training.

#### QUALITY

Access to health care is only the first step in protecting the health of all children and youth. We must ensure that the care provided is of the highest quality. Robust Federal support for the wide array of quality improvement initiatives, including research, is needed if this goal is to be achieved.

*Emergency Services for Children.*—One program that assists local communities in providing quality care to children in distress is the Emergency Medical Services for Children (EMSC) grant program. There are approximately 30 million child and adolescent visits to the Nation’s emergency departments every year. Children under the

age of 3 years account for most of these visits. Up to 20 percent of children needing emergency care have underlying medical conditions such as asthma, diabetes, sickle-cell disease, low birth weight, and bronchopulmonary dysplasia. In 2006, the Institute of Medicine's report *Emergency Care for Children: Growing Pains* acknowledged the many achievements of the EMSC program in improving pediatric emergency care and recommended that it be funded at \$37.5 million. In order to assist local communities in providing the best emergency care to children, we once again reject the administration's proposed elimination of the EMSC program and strongly urge that the EMSC program be maintained and adequately funded at \$25 million in fiscal year 2008.

*Agency for Healthcare Research and Quality.*—Quality of care rests on quality research—for new detection methods, new treatments, new technology and new applications of science. As the lead Federal agency on quality of care research, the Agency for Healthcare Research and Quality (AHRQ) provides the scientific basis to improve the quality of care, supports emerging critical issues in health care delivery and addresses the particular needs of priority populations, such as children. Substantial gaps still remain in what we know about health care needs for children and adolescents and how we can best address those needs. Children are often excluded from research that could address these issues. The AAP and endorsing organizations strongly support AHRQ's objective to encourage researchers to include children and adolescents as part of their research populations. We also support increasing AHRQ's efforts to build pediatric health services research capacity through career and faculty development awards and strong practice-based research networks. Additionally, AHRQ is focusing on initiatives in community and rural hospitals to reduce medical errors and to improve patient safety through innovative use of information technology—an initiative that we hope would include children's hospitals as well. Through its research and quality agenda, AHRQ continues to provide policymakers, health care professionals and patients with critical information needed to improve health care and health disparities. We join with the Friends of AHRQ to recommend funding of \$350 million for AHRQ in fiscal year 2008.

*National Institutes of Health.*—Over the years, NIH has made dramatic strides that directly impact the quality of life for infants, children and adolescents through biomedical and behavioral research. For example, NIH research has led to successfully decreasing infant death rates by over 70 percent, increasing the survival rates from respiratory distress syndrome, and dramatically reducing the transmission of HIV from infected mother to fetus and infant from 25 percent to just 1.5 percent. NIH is engaged in a comprehensive research initiative to address and explain the reasons for a major public health dilemma—the increasing number of obese and overweight children and adults in this country. Today U.S. teenagers are more overweight than young people in many other developed countries. And the Newborn Screening Initiative is moving forward to improve availability, accessibility, and quality of genetic tests for rare conditions that can be uncovered in newborns. The pediatric community applauds the prior commitment of Congress to maintain adequate funding for the NIH. We remain concerned, however, that the cumulative effect of several years of flat funding will stall or even set back the gains that were made under the years of the NIH's budget doubling. We urge you to begin to restore the funding lost over these last years. We support the recommendation of the Ad Hoc Group for Medical Research for a funding level in fiscal year 2008 of \$30.8 billion an increase of 6.7 percent over the fiscal year 2007 joint resolution for the NIH. In addition, to ensure ongoing and adequate child and adolescent focused research, such as the National Children's Study (NCS) led by the National Institute for Child Health and Human Development (NICHD), we join with the Friends of NICHD Coalition in requesting \$1,337.8 billion in fiscal year 2008. Moreover we recommend that the NCS be adequately funded in fiscal year 2008 at \$110.9 million to allow for the continued implementation of the NCS and bring us closer to the first results from this landmark study. We are greatly disappointed by the administration's failure to include the NCS in its budget proposal 2008. This large longitudinal study, authorized in the Children's Health Act of 2000, will provide critical research and information on major causes of childhood illnesses such as premature birth, asthma, obesity, preventable injury, autism, development delay, mental illness, and learning disorders.

We commend this committee's ongoing efforts to make pediatric research a priority at the highest level of the NIH. We urge continued Federal support of NIH efforts to increase pediatric biomedical and behavioral research, including such proven programs as targeted training and education opportunities and loan repayment. We recommend continued interest in and support for the Pediatric Research Initiative in the Office of the NIH Director and sufficient funding to continue the pediatric training grant and pediatric loan repayment programs both enacted in the

Children's Health Act of 2000. This would ensure that we have adequately trained pediatric researchers in multiple disciplines that will not come at the expense of other important programs.

Finally, as clinicians, we know first-hand the considerable benefits for children and society in securing properly studied and dosed medications. Proper pediatric safety and dosing information reduces medical errors and adverse events, ultimately improving children's health and reducing health care costs. But there is little market incentive for drug companies to study generic or off-patent drugs—older drugs that are widely used therapies for children. The Research Fund for the Study of Drugs, created as part of the Best Pharmaceuticals for Children Act of 2002, provides support for these critical pediatric testing needs, but unfortunately is currently funded at an amount sufficient to test only a fraction of the NIH and FDA-designated “priority” drugs. Therefore, we urge the subcommittee to provide the NIH with sufficient funding to fund the study of generic (off-patent) drugs for pediatric use.

#### IMMUNIZATION

Pediatricians, working alongside public health professionals and other partners, have brought the United States its highest immunization coverage levels in history—over 92 percent of children received all vaccinations by school age in 2004–2005. We attribute this, in part, to the Vaccines for Children (VFC) Program, and encourage Congress to maintain its commitment to ensuring the program's viability. The VFC program combines the efforts of public health and private pediatricians and other health care professionals to accomplish and sustain vaccine coverage goals for both today's and tomorrow's vaccines. It removes vaccine cost as a barrier to immunization for some and reinforces the concept of vaccine delivery in a “medical home.” Additional section 317 funding is necessary to provide the pneumococcal conjugate vaccine (PCV-7), a vaccine that prevents an infection of the brain covering, blood infections and approximately 7 million ear infections a year, to those remaining States that currently do not provide it. Increased section 317 funding also is needed to purchase the influenza vaccine—now recommended for children between the ages of 6 months and 5 years of age. This age cohort is increasingly susceptible to serious infection and the risk of hospitalization. And an increase in funding is needed to purchase the recently recommended rotavirus vaccine, tetanus-diphtheria-pertussis (Tdap) vaccine for adolescents and the meningococcal conjugate vaccine (MCV). Meningococcal disease is a serious illness, caused by bacteria, with 10–15 percent of cases fatal and another 10–15 percent of cases resulting in permanent hearing loss, mental retardation, or loss of limbs. And additional funding is important to provide the HPV vaccine recommended by the ACIP.

The public health infrastructure that now supports our national immunization efforts must not be jeopardized with insufficient funding. For example, adolescents continue to be adversely affected by vaccine-preventable diseases (e.g., chicken pox, hepatitis B, measles and rubella). Comprehensive adolescent immunization activities at the national, State, and local levels are needed to achieve national disease elimination goals. States and communities continue to be financially strapped and therefore, many continue to divert funds and health professionals from routine immunization clinics in order to accommodate anti-bioterrorism initiatives or now pandemic influenza. Moreover, continued investment in the CDC's immunization activities must be made to avoid the reoccurrence of childhood vaccine shortages by providing and adequately funding a national 6 month stockpile for all routine childhood vaccines—stockpiles of sufficient size to insure that significant and unexpected interruptions in manufacturing do not result in shortages for children.

While the ultimate goal of immunizations clearly is eradication of disease, the immediate goal must be prevention of disease in individuals or groups. To this end, we strongly believe that CDC's efforts must be sustained. In fiscal year 2008, we recommend an overall increase in funding to \$802.4 million \$257.5 million over the President's request to ensure that the CDC's National Immunization Program has the funding necessary to accommodate vaccine price increases, new disease preventable vaccines coming on the market, global immunization initiatives—including funds for polio eradication and the elimination of measles and rubella—and to continue to implement the recommendations developed by the IOM.

#### CONCLUSION

We appreciate the opportunity to provide our recommendations for the coming fiscal year. As this subcommittee is once again faced with difficult choices and multiple priorities we know that as in the past years, you will not forget America's children and adolescents.

## PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 60,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on fiscal year 2008 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the Academy supports the HPNEC recommendation to provide at least \$300 million for Title VII programs in fiscal year 2008, including a minimum of \$7 million to support PA educational programs. This would fund the programs at the 2005 funding level, not accounting for inflation.

The Academy believes that the recommended restoration in funding for Title VII health professions programs is well justified. A review of PA graduates from 1990–2004 reveals that graduates from Title VII supported programs were 67 percent more likely to be from underrepresented minority backgrounds and 49 percent more likely to work in a Rural Health Clinic than graduates of programs that weren't supported by Title VII funding.

Title VII safety net programs are essential to the training of primary health care professionals and provide increased access to care by promoting health care delivery in medically underserved communities. Title VII funding for PA programs is especially important since it is the only Federal funding available to these programs, on a competitive application basis.

The Academy is extremely concerned with the administration's proposal to eliminate funding for most Title VII programs, including training programs in primary care medicine and dentistry. These programs are designed to help meet the health care delivery needs of the Nation's Health Professional Shortage Areas (HPSAs). By definition, the Nation's more than 5,500 HPSAs experience shortages in the primary care workforce that the market alone can't address. In addition, the Health Resources and Services Administration (HRSA) predicts that there will be a need for over 11,000 health care professionals to implement the President's Community Health Center (CHC) Initiative. The increased funding for these CHCs will provide medical care to approximately 6 million people in the United States. Title VII serves as crucial funding for the pipeline of health professionals that serve CHCs today.

We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to restore funding to these important programs in fiscal year 2008 to the fiscal year 2005 funding level.

## OVERVIEW OF PHYSICIAN ASSISTANT EDUCATION

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about 4 years of prior health care experience. The first phase of the program consists of more than 400 hours in classroom and laboratory instruction in the basic sciences, over 75 hours in pharmacology, approximately 175 hours in behavioral sciences, and almost 580 hours of clinical medicine.

The second year of PA education consists of clinical rotations, which typically includes more than 2,000 hours or 50–55 weeks of clinical education, divided between primary care medicine and various specialties. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

After graduation from an accredited PA program, physician assistants must pass a national certifying examination jointly developed by the National Board of Medical Examiners and the independent National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education credits every 2 years, and they must take a recertification exam every 6 years.

## PHYSICIAN ASSISTANT PRACTICE

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all States, physicians may delegate to PAs those medical duties that are within the physician's scope of practice and the PA's training and experience and are allowed by law. Physicians may also delegate prescriptive privileges to the PAs they supervise. PAs are located in almost all health care settings and medical and surgical specialties. Six-

teen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (State laws stipulate the conditions for remote supervision by a physician). Approximately 48 percent of PAs work in urban and inner city areas. Approximately 38 percent of PAs are in primary care. In 2006, an estimated 231 million patient visits were made to PAs and approximately 286 million medications were prescribed or recommended by PAs.

#### CRITICAL ROLE OF TITLE VII PUBLIC HEALTH SERVICE ACT PROGRAMS

A growing number of Americans lack access to primary care either because they are uninsured, underinsured, or they live in a community with an inadequate supply or distribution of providers. The growth in the uninsured U.S. population increased from approximately 32 million in the early 1990s to almost 47 million today. The role of Title VII programs is to alleviate these problems by supporting educational programs that train more health professionals in fields experiencing shortages, improving the geographic distribution of health professionals, and increasing access to care in underserved communities.

Title VII programs are the only Federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. Furthermore, GME was not intended to generate a supply of providers who are willing to work in the Nation's medically underserved communities. That is the purpose of the Title VII Public Health Service Act programs.

In addition, as evidence indicates that race and ethnicity correlate to persistent health disparities among U.S. populations, it is essential to increase the diversity of health care professionals. Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations. This is particularly important, as studies have found that those from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care.

#### TITLE VII SUPPORT OF PA EDUCATIONAL PROGRAMS

Targeted Federal support for PA educational programs is authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, Public Law 105-392, which streamlined and consolidated the Federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

Public Law 105-392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to an affordable education and encourage PAs, upon graduation, to practice in underserved communities. These goals are accomplished by funding PA educational programs that have a demonstrated track record of (1) placing PA students in health professional shortage areas; (2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and (3) recruiting and retaining students who are indigenous to communities with unmet health care needs.

The PA programs' success is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of Web based and distant learning technology, so students can remain at clinical practice sites. A PA program in New York, where over 90 percent of the students are ethnic minorities, uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the special, unmet needs of medically underserved areas or

disadvantaged students. The need is very real, and Title VII is critical in meeting that need.

#### NEED FOR INCREASED TITLE VII SUPPORT FOR PA EDUCATIONAL PROGRAMS

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 31 percent of PAs met their first clinical employer through their clinical rotations.

The supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 2006 article in the *Journal of the American Medical Association (JAMA)* concluded that the Federal Government should augment the use of physician assistants as physician substitutes, particularly in urban CHCs where the proportional use of physicians is higher. The article suggested that this could be accomplished by adequately funding Title VII programs. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 49 percent between 2004 and 2014. Title VII funding has provided a crucial pipeline of trained PAs to underserved areas.

Despite the increased demand for PAs, funding has not proportionately increased for Title VII programs that are designed to educate and place PAs in underserved communities. Nor has Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2004 indicates an average annual increase of 7 percent, a total increase of 256 percent over the past 20 years, yet Federal support has decreased.

#### RECOMMENDATIONS ON FISCAL YEAR 2008 FUNDING

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for fiscal year 2008. For instance, while it is important to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if HRSA is inadequately funded. HRSA administers the "people" programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, training is the key to emergency preparedness, and Title VII, section 747, is the ideal mechanism for educating primary care providers in public health competencies that ensures the CDC has an adequate supply of health care providers to report, track, and contain disease outbreaks.

The Academy respectfully requests that Title VII health professions programs receive \$300 million in funding for fiscal year 2008, including a minimum of \$7 million to support PA educational programs. Thank you for the opportunity to present the American Academy of Physician Assistants' views on fiscal year 2008 appropriations.

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#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

##### EXECUTIVE SUMMARY

The American Association for Cancer Research (AACR) would like to thank Members for their support of National Institutes of Health (NIH) and National Cancer Institute (NCI) research on the biology, treatment and prevention of the more than 200 diseases called cancer. The AACR, with more than 25,000 members worldwide, represents and supports scientists by publishing respected, peer-reviewed scientific journals, hosting international scientific conferences, and awarding millions of dollars in research grants. Together, we have made great strides in the war on cancer, but much remains to be done. One in four deaths in America this year will be caused by cancer. Cancer-related deaths will increase dramatically as the baby boom generation ages, and we must be prepared to prevent, treat, and manage the impending wave of new cancers.

Cancer is no longer a death sentence thanks to decades of research and development made possible by strong commitments from Congress and the American peo-

ple, but now that commitment is wavering. After expanding capacity during the NIH budget doubling, researchers at hospitals and universities across the country now face shrinking budgets. Promising young researchers, unable to secure grants, turn to other careers. This disruption of the research pipeline will slow the development of new treatments and set back America's biomedical leadership for decades to come.

We are at the vanguard of a revolution in healthcare, where personalized treatment will improve health, reduce harmful side effects, and lower costs. We have the opportunity to build upon our previous investments and accelerate the research process. Now is the time to face the Nation's growing healthcare needs, reaffirm our role as world leaders in science, and renew our commitment to the research and development that brings hope to millions of suffering Americans. The AACR urges the U.S. Senate to support the following appropriations funding levels for cancer research in fiscal year 2008:

- \$30.8 billion for the National Institutes of Health, a 6.7 percent increase over fiscal year 2007.
- \$5.8 billion for the National Cancer Institute (the NCI Professional Judgment budget level), or, at a minimum, \$5.1 billion, a 6.7 percent increase over fiscal year 2007.

The American Association for Cancer Research (AACR) recognizes and expresses its thanks to the United States Congress for its longstanding support and commitment to funding cancer research. The completion of the 5-year doubling of the budget of the National Institutes of Health (NIH) in 2003 was a stunning accomplishment that is already showing impressive returns and benefits to patients with cancer. Recently, however, budgets for cancer research have declined; this commitment appears to be wavering. Budget doubling enabled a significant expansion of infrastructure and scientific opportunities. Budget cuts prevent us from capitalizing on them.

Unquestionably, the Nation's investment in cancer research is having a remarkable impact. Cancer deaths in the United States have declined for the second year in a row. Last year's decline was the first such decrease in the total number of annual cancer deaths since 1930 when record-keeping began. This progress occurred in spite of an aging population and the fact that more than three-quarters of all cancers are diagnosed in individuals aged 55 and older. Yet this good news will not continue without sustained and substantial Federal funding for critical cancer research priorities. The American Association for Cancer Research joins the broader biomedical research community in urging the United States Senate to support the following appropriations funding levels for cancer research in fiscal year 2008:

- \$30.8 billion for the National Institutes of Health, a 6.7 percent increase over fiscal year 2007.
- \$5.8 billion for the National Cancer Institute (the NCI Professional Judgment budget level), or, at a minimum, \$5.1 billion, a 6.7 percent increase over fiscal year 2007.

#### AACR: FOSTERING A CENTURY OF RESEARCH PROGRESS

The American Association for Cancer Research has been moving cancer research forward since its founding 100 years ago in 1907. Celebrating its Centennial Year, the AACR and its more than 25,000 members worldwide strive tirelessly to carry out its important mission to prevent and cure cancer through research, education, and communication. It does so by:

- fostering research in cancer and related biomedical science;
- accelerating the dissemination of new research findings among scientists and others dedicated to the conquest of cancer;
- promoting science education and training; and
- advancing the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world.

#### FACING AN IMPENDING CANCER "TSUNAMI"

Over the past 100 years, enormous progress has been made toward the conquest of the Nation's second most lethal disease (after heart disease). Thanks to discoveries and developments in prevention, early detection, and more effective treatments, many of the more than 200 diseases called cancer have been cured or converted into manageable chronic conditions while preserving quality of life. The 5-year survival rate for all cancers has improved over the past 30 years to more than 65 percent. The completion of the doubling of the NIH budget in 2003 is bearing fruit as many new and promising discoveries are unearthed and their potential real-

ized. However, there is much left to be done, especially for the most lethal and rarer forms of the disease.

We recognize that the underlying causes of the disease and its incidence have not been significantly altered. The fact remains that men have a 1 in 2 lifetime risk of developing cancer, while women have a 1 in 3 lifetime risk. The leading cancer sites in men are the prostate, lung and bronchus, and colon and rectum. For women, the leading cancer sites are breast, lung and bronchus, and colon and rectum. And cancer still accounts for 1 in 4 deaths, with more than 564,830 people expected to die from their cancer in 2006. Age is a major risk factor—this Nation faces a virtual “cancer tsunami” as the baby boomer generation reaches age 65 in 2011. A renewed commitment to progress in cancer research through leadership and resources will be essential to dodge this cancer crisis.

#### FEDERAL INVESTMENT FOR LOCAL BENEFIT

Nearly half of the NCI budget is allocated to research project grants that are awarded to outside scientists who work at local hospitals and universities throughout the country. More than 5,400 research grants are funded at more than 150 cancer centers and specialized research facilities located in 49 States. Over half the States receive more than \$15 million in grants and contracts to institutions located within their borders. Many AACR member scientists are engaged in this rewarding work. But too many of them have had their long-term research jeopardized by grant reductions caused by the flat and declining overall funding for the NCI since 2003. The AACR recommends, at a minimum, a 6.7 percent increase in funding for the National Cancer Institute to enable it to continue and expand its work on focused research questions.

#### UNDERSTANDING THE CAUSES AND MECHANISMS OF CANCER

Basic research into the causes and mechanisms of cancer is at the heart of what the NCI and many of AACR's member scientists do. Basic research is the engine that drives scientific progress. The outcomes from this fundamental basic research—including laboratory and animal research in addition to population studies and the deployment of state-of-the-art technologies—will inform and drive the cancer research enterprise in ways and directions that will lead to unparalleled progress in the search for cures.

#### ACCELERATING PROGRESS IN CANCER PREVENTION

Preventing cancer is far more cost-effective and desirable than treating it. The NCI uses multidisciplinary teams and a systems biology approach to identify early events and how to modify them. More than half of all cancers are related to modifiable behavioral factors, including tobacco use, diet, physical inactivity, sun exposure, and failure to get cancer screenings. The NCI supports research to understand how people perceive risk, make health-related decisions, and maintain healthy behavior. Prevention is the keystone to success in the battle against cancer.

#### DEVELOPING EFFECTIVE AND EFFICIENT TREATMENTS

The future of cancer care is all about developing individualized therapies tailored to the specific characteristics of a patient's cancer. Noteworthy recent advances in this area have included the development of oral versions of medicines that were formerly only available by injection, thus improving patients' quality of life; and the discovery of intraperitoneal (IP) chemotherapy—delivering drugs directly to the abdominal cavity—that can add more than a year to survival for some women with ovarian cancer.

#### OVERCOMING CANCER HEALTH DISPARITIES

Some minority and underserved population groups suffer disproportionately from cancer. Solving this issue will contribute significantly to reducing the cancer burden. Successful achievements in this important area include the development and dissemination of the patient navigator program that assists patients and caregivers to access and chart a course through the healthcare system, and the NCI Cancer Information Services Partnership Program that provides information and education about cancer in lay language to the medically underserved through community organizations.

## AACR'S INITIATIVES AUGMENT SUPPORT FOR THE NCI

The NCI is not working alone or in isolation in any of these key areas. NCI research scientists reach out to other organizations to further their work. The AACR is engaged in scores of initiatives that strengthen, support, and facilitate the work of the NCI, including:

- sponsoring the largest meeting of cancer researchers in the world, with more than 17,000 scientists and 6,000 abstracts featuring the latest scientific advances;
- publishing more than 3,400 original research articles each year in five prestigious peer-reviewed scientific journals, including *Cancer Research*;
- sponsoring the annual International Conference on Frontiers of Cancer Prevention Research, the largest such prevention meeting of its kind in the world;
- raising and distributing more than \$5 million in awards and research grants.

## TRAINING AND CAREER DEVELOPMENT FOR THE NEXT GENERATION OF RESEARCHERS

Of critical importance to the viability of the long-term cancer research enterprise is supporting, fostering, and mentoring the next generation of investigators. The NCI devotes approximately 4 percent of its budget to multiple strategies to training and career development, including sponsored traineeships, a Medical Scientist Training Program, special set-aside grant programs and bridge grants for early career cancer investigators. Increased funding for these foundational opportunities is essential to retain the scientific workforce that is needed to continue the fight against cancer.

## INCREASE RESEARCH FUNDING NOW

Remarkable progress is being made in cancer research, but much more remains to be done. Cancer costs the Nation more than \$209 billion in direct medical costs and lost productivity due to illness and premature death. Respected University of Chicago economists Kevin Murphy and Robert Topel have estimated that even a modest 1 percent reduction in mortality from cancer would be worth nearly \$500 billion in social value. Investments in cancer research have huge potential returns. Thanks to successful past investments, promising research opportunities abound and must not be lost. To maintain our research momentum, the American Association for Cancer Research (AACR) urges the United States Senate to support the following appropriations funding levels for cancer research in fiscal year 2008:

- \$30.8 billion for the National Institutes of Health, a 6.7 percent increase over fiscal year 2007.
- \$5.8 billion for the National Cancer Institute (the NCI Professional Judgment budget level), or, at a minimum, \$5.1 billion, a 6.7 percent increase over fiscal year 2007.

## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) respectfully submits this statement highlighting funding priorities for nursing education and research programs in fiscal year 2008. AACN represents more than 600 schools of nursing at public and private universities and senior colleges with baccalaureate and graduate nursing programs that educate over 240,000 students and employ over 12,000 faculty members. These institutions are responsible for educating almost half of our Nation's registered nurses (RNs) and all of the nurse faculty and researchers. Nursing represents the largest health profession, with approximately 2.9 million dedicated, trusted professionals delivering primary, acute, and chronic care to millions of Americans.

## NATIONWIDE NURSING SHORTAGE

For nearly a decade, our country's health care system has been negatively impacted by a shortage of RNs. In 2002, the Joint Commission on Accreditation of Healthcare Organizations noted that the nursing shortage contributed to nearly a quarter of all unexpected incidents that adversely affect hospitalized patients. A more recent comprehensive analysis published in the March 2006 issue of *Nursing Economic\$* found that the majority of nurses reported that the RN shortage is negatively impacting patient care and undermining the quality of care goals set by the Institute of Medicine and the National Quality Forum. Unfortunately, reports reveal that the nursing shortage is not expected to diminish in the foreseeable future. The Bureau of Labor Statistics projects that more than 1.2 million new and replacement

nurses will be needed by 2014. Government analysts further project that more than 703,000 new RN positions will be created through 2014, which will account for two-fifths of all new jobs in the health care sector.

A number of contributing factors add to the complexity and duration of the shortage. Within the next 20 years, there will be a wave of nurses retiring from the profession. According to the 2004 National Sample Survey of Registered Nurses released in February 2007 by the Federal Division of Nursing, the average age of the RN population in March 2004 was 46.8 years of age, up from 45.2 in 2000. With many nurses nearing the age of retirement, more nurses must enter the pipeline. However, the nursing profession is not growing to meet the demand of the shortage. While The National Sample Survey of Registered Nurses has indicated that the total RN population has increased at every 4-year interval since 1980, the growth from 2000 to 2004 was relatively low. The total RN population increased by only 7.9 percent in 2004. Earlier report intervals noted that the RN population grew by 14.2 percent between 1992 and 1996.

The approximately 1,500 schools of nursing nationwide have been working diligently to expand enrollments. AACN's 2006–2007 annual survey of 722 nursing schools with baccalaureate and graduate programs reveals that enrollments increased by 7.6 percent in entry-level baccalaureate nursing programs.

This makes the sixth consecutive year of enrollment increases that can be attributed to a combination of Federal support, private sector marketing efforts, public-private partnerships providing additional resources to expand capacity of nursing programs, and State legislation targeting funds towards nursing scholarships and loan repayment. While essential and important, these efforts have not fully met the increasing demand for RNs.

Health Resources and Services Administration (HRSA) officials stated in an April 2006 report that there must be a 90 percent increase in graduations from U.S. nursing programs in order to meet the demand for RN services. Yet, the inability of nursing schools to educate more RNs is the most urgent contributing factor that must be addressed in order to reverse the shortage and ensure that every patient receives the safest, highest quality health care. According to AACN's report on 2006–2007 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing, U.S. nursing schools turned away 42,866 qualified applicants to baccalaureate and graduate programs due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Almost three quarters of the nursing schools responding to the AACN survey pointed to faculty shortages as a reason for not accepting all qualified applicants into nursing programs. Federal support must continue to play an integral role in our Nation's efforts to address the nursing and nurse faculty shortage as well as the constraints encountered by nursing's educational system.

#### NURSING WORKFORCE DEVELOPMENT PROGRAMS: ADDRESSING THE SHORTAGE

Acknowledging the severity of the Nation's nursing shortage, Congress passed The Nurse Reinvestment Act of 2002. This legislation created new programs and expanded existing Nursing Workforce Development authorities. Administered by HRSA under Title VIII of the Public Health Service Act, these programs focus on the supply and distribution of RNs across the country. The programs support individual students in their nursing studies through scholarships and loan repayment programs. Title VIII programs stimulate innovation in nursing practice and bolster nursing education throughout the continuum, from entry-level preparation through graduate study. They are the largest source of Federal funding for nursing education assisting students, schools of nursing, and health systems in their efforts to educate, recruit, and retain RNs and nurse faculty. In fiscal year 2006, these programs helped to educate over 48,000 nursing students and nurses through individual and programmatic support.

However, funding for these authorities is insufficient to address the severity of the nursing and nurse faculty shortage. Currently, Nursing Workforce Development Programs receive \$149.68 million, the same funding level as in fiscal year 2006. During the nursing shortage in 1974, Congress appropriated \$153 million for nursing education programs. Translated into today's dollars, that appropriation would total \$632 million, more than four times the current level. To fully meet the educational and practice demands of today's nursing shortage it would take billions of dollars.

AACN respectfully requests \$200 million for Title VIII Nursing Workforce Development Programs in fiscal year 2008, an additional \$50.32 million over the fiscal year 2007 level. New monies would expand nursing education, recruitment, and retention efforts to help resolve all aspects adding to the nursing shortage.

### *Nurse Faculty Shortage*

AACN believes that the most effective strategy to resolve the nursing shortage is addressing the underlying nurse faculty shortage. The demand for nurse faculty far exceeds the rate at which nursing schools can educate them. HRSA reports that just 13 percent of the RN workforce holds either a master's or doctoral degree, the credentials required to teach. A Special Survey on Vacant Faculty Positions released by AACN in July 2006, reported a total of 637 faculty vacancies (8 percent vacancy rate) were identified at 329 nursing schools with baccalaureate and/or graduate programs across the country (almost two vacancies at each school of nursing). Most of the vacancies (53.7 percent) were faculty positions requiring a doctoral degree. Besides the vacancies, schools cited the need to create an additional 55 faculty positions to accommodate student demand. The ability to increase the pool of educators becomes increasingly difficult when 3,306 qualified applicants were turned away from master's programs and 299 qualified applicants were turned away from doctoral programs in 2006.

The inability of nursing schools to educate, recruit, and retain qualified teachers is fueling the nurse faculty shortage. Potential faculty members graduating from schools of nursing are slow to rise. In 2006, graduations from research-focused doctoral nursing programs were up by only 1.4 percent or six graduates from the 2005–2006 academic year. Complicating the problem further, those that are graduating from schools of nursing with a graduate degree are not choosing a career in education. An unpublished AACN study on employment plans found that almost a quarter of all graduates from doctoral nursing programs do not plan to work in academic settings. Higher compensation in clinical and private sector settings lures current and potential nurse educators away from the classroom.

Furthermore, the demand for nurse faculty will continue to grow in the very near future as schools of nursing will experience an increase in faculty retirement. According to an article published in the March/April 2002 issue of *Nursing Outlook* titled *The Shortage of Doctorally Prepared Nursing Faculty: A Dire Situation*, the average age of nurse faculty at retirement is 62.5 years. With the average age of doctorally-prepared faculty currently 53.5 years, a wave of retirements is expected within the next 10 years. Without sufficient nurse faculty, schools of nursing cannot expand enrollments, and the nursing shortage will continue to cripple our Nation's health care delivery system.

#### REVERSING THE NURSE FACULTY SHORTAGE AND NURSING EDUCATIONAL BARRIERS

The Nursing Workforce Development programs are essential in not only educating nurses, but more critically, in funding the education of additional nurse faculty. In fiscal year 2008, AACN recommends increasing funding for graduate education through the Advanced Education Nursing (AEN) Grants (Sec. 811) and bolstering funds for the Nurse Faculty Loan Program (Sec. 846A) as well as the Nurse Education, Practice, and Retention Grants (Sec. 831). These programs are essential in educating nurses, but more importantly in funding the education of nurse faculty, which allow schools of nursing to increase their student capacity.

*Advanced Education Nursing Program (Sec. 811).*—These grants support the majority of nursing schools preparing graduate-level nurses, many of whom become faculty. Receiving \$57.06 million in fiscal year 2007, this grant program helps schools of nursing, academic health centers, and other nonprofit entities improve the education and practice of nurse practitioners, nurse-midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and clinical nurse specialists. Out of the 114 applications reviewed for program grants in fiscal year 2006, 45 new grants were awarded and 112 previously awarded grants were continued, totaling 157—the same number as in fiscal year 2004 and fiscal year 2005. In addition, 564 schools of nursing received traineeship grants, which in turn directly supported 9,000 individual student nurses. In fact, 2,105 nurses who received support from AEN grants in fiscal year 2006 are now practicing in underserved areas.

*Nurse Faculty Loan Program (Sec. 846A).*—Designed to increase the number of nurse faculty, schools of nursing receive grants to create a loan fund through the Nurse Faculty Loan Program. To be eligible for these loans, students must pursue full-time study for a master's or doctoral degree. In exchange for teaching at a school of nursing, loan recipients will have up to 85 percent of their educational loans cancelled over a 4-year period. In fiscal year 2006, 67 new grants and 26 continuing grants were awarded to schools of nursing. These grants are projected to assist 475 future nurse educators. Unfortunately, in fiscal year 2006 schools of nursing requested over three times the funds available to educate additional nurse faculty. In fiscal year 2007, \$4.77 million was appropriated. If the current funding was doubled to almost \$10 million, based on fiscal year 2006 projections, nursing schools

could educate over 900 future faculty members. Further, with an average faculty to student ratio of 1:10, those 900 faculty members could teach an additional 9,000 nurses each year.

*Nurse Education, Practice, and Retention Grants (Sec. 831).*—These grants help schools of nursing, academic health centers, nurse-managed health centers, State and local governments, and health care facilities strengthen programs that provide nursing education. In particular, the Education Grants expand enrollments in baccalaureate nursing programs. In addition, they develop internship and residency programs to enhance mentoring and specialty training as well as provide for new technology in education, including distance learning.

#### NATIONAL INSTITUTE OF NURSING RESEARCH

One of the 27 Institutes and Centers at the National Institutes of Health, the National Institute of Nursing Research (NINR) works to improve patient care and foster advances in nursing and other health professions' practice. The outcomes-based findings derived from NINR research are important to the future of the health care system and its ability to deliver safe, cost-effective, and high quality care. Through grants, research training, and interdisciplinary collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life in those with chronic illness, and care for individuals at the end of life. To advance this research, AACN respectfully requests a funding level of \$150 million in fiscal year 2008, an additional \$12.66 million over the \$137.34 million, NINR received in fiscal year 2007,

#### *NINR Addresses the Shortage of Nurse Researchers and Faculty*

NINR allocates 7 percent of its budget, a high proportion when compared to other NIH institutes, to research training to help develop the pool of nurse researchers. In fiscal year 2005, NINR training dollars supported 80 individual researchers and provided 155 institutional awards, which in turn supported a number of nurse researchers at each institution. Since nurse researchers often serve as faculty members for colleges of nursing, they are actively educating our next generation of RNs.

#### CONCLUSION

AACN acknowledges the fiscal challenges that the subcommittee and the entire Congress must work within. However, the nursing shortage can no longer be explained by the need to simply increase the number of nurses in the workforce. A demand for nurse educators weighs heavily on the ability to increase the pool of future nurses. This element of the shortage has created a negative chain reaction—without more nurse faculty, additional nurses cannot be educated, and without more nurses the shortage will continue. Ultimately, this chain reaction will continue to place the health care delivery system at risk. Title VIII programs can help to break this chain. These authorities provide a dedicated, long-term vision for supporting the education of the new nursing workforce. Yet, they must receive additional funding to be effective. AACN respectfully requests \$200 million for Title VIII programs in fiscal year 2008. Additional funding for these programs will assist schools of nursing to expand their programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our health care system. AACN also requests \$150 million for NINR so that nurse researchers can continue their work to improve the nursing care provided to all patients.

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#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), which represents the administrations, faculties, and students of all twenty-three colleges of osteopathic medicine in the United States, I am pleased to present our views on the fiscal year 2008 appropriations for Health Professions Education Programs under Title VII of the Public Health Service Act.

First, we want to express our profound concern at the devastating cuts sustained by the Title VII programs in appropriations for the last two fiscal years. The fiscal year 2006 Labor, Health and Human Services, Education and Related Agencies Appropriations bill cut Title VII programs from the fiscal year 2005 level by 51.5 percent. Unfortunately, the fiscal year 2007 funding level restored only a small fraction of these cuts.

Health Professions Education Programs under Title VII are essential components of America's health care safety net. An adequate, diverse, well-distributed and cul-

turally competent health workforce is indispensable to meeting our current and especially our future health service delivery needs. The Title VII programs have been especially valuable in our efforts to ensure continuation of this commitment. In Public Law 105-392, the Health Professions Education Partnership Act of 1998, forty-four different Federal health professions training programs were consolidated into seven clusters. These clusters provide support for training of primary care medicine and dental providers; the establishment and operation of interdisciplinary community-based training activities; health professions workforce analysis; public health workforce development; nursing education; and student financial assistance. These programs are designed to meet the health care delivery needs of over 2,800 Health Professions Shortage Areas in the country. Many rural and disadvantaged populations depend on the health professionals trained by these programs as their only source of health care. For example, without the practicing family physicians who are currently in place, an additional 1,332 of the United States' 1,082 urban and rural counties would qualify for designation as primary care Health Professions Shortage Areas.

Title VII programs have had a significant impact in reducing the Nation's Health Professions Shortage Areas. Indeed, a 1999 study estimated that if funding for Title VII program were doubled, the effect would be to eliminate the Nations' Health Professions Shortages Areas in as little as 6 years. (Poltzer, RM, Hardwick, KC, Cultice, JM, Bazell, C. "Eliminating Primary Care Health Professions Shortage Areas: The Impact of Title VII Generalist Physician Education," *The Journal of Rural Health*, 1999; 15(1): 11-19).

A study by the Robert Graham Center showed that receipt of Title VII family medicine grants by medical schools produced more family physicians and more primary care doctors serving in rural areas and Health Professions Shortage Areas. Over 69 percent of Title VII funded internal medicine graduates practice primary care after graduation. This rate is nearly twice that of programs not receiving Title VII funding.

Among the programs within these clusters that have been especially important to enhancing osteopathic medical schools' ability to train the highest quality physicians are: General Internal Medicine Residencies; General Pediatric Residencies; Family Medicine Training; Preventive Medicine Residencies; Area Health Education Centers (AHECs); Health Education and Training Centers (HETCs); Health Careers Opportunity Programs (HCOP); Centers of Excellence (COE) programs; and Geriatric Training Authority.

Accordingly, Mr. Chairman and Members of the subcommittee, AACOM recommends that the fiscal year 2008 funding for Title VII Health Professions Education Programs and the equally important programs under Title VIII, Nursing Education be at least \$550 million. This figure is consistent with the fiscal year 2008 level recommended by the Health Professions and Nursing Education Coalition (HPNEC) for Titles VII and VIII.

AACOM also strongly urges continuation of funding for the Council on Graduate Medical Education (COGME). Since its inception, COGME's diverse membership has given the health policy community an opportunity to discuss national workforce issues. The fifteen formal reports and multiple ancillary materials provided by COGME have offered important findings and observations in the rapidly changing health care environment and have argued for a system of graduate medical education that develops a physician workforce to meet the healthcare needs of the American people.

Some of the more significant recommendations include:

- Community-based education with an emphasis on primary care;
- Continued progress toward a more representative participation of minorities in medicine;
- The development and maintenance of a workforce planning infrastructure to improve the understanding, need and demand forces;
- The development of Federal-State partnerships to further workforce planning; and
- Encouragement and support for medical education and health care delivery programs that increase the flow of physicians to rural areas, with an emphasis on the smaller, more remote communities.

With a projected physician workforce shortage looming, the activities of COMGE have never been more important.

Mr. Chairman and members of the subcommittee, we appreciate the opportunity to submit this statement. If you have any questions or require additional information, please contact me at (301) 968-4141 or sshannon@aacom.org, or Michael J. Dyer, AACOM's Vice President for Government Relations at (301) 968-4152 or mdyer@aacom.org.

## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF PHARMACY

## HHS SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY

AACP and its member colleges and schools of pharmacy appreciate the continued support of the House Appropriations Subcommittee on Labor, Health and Human Services, and Education. The 97 accredited colleges and schools of pharmacy are engaged in a wide-range of programs that are supported by grants and funding administered through the agencies of the Department of Health and Human Services (HHS). We also understand the difficult task you face annually in your deliberations to do the most good for the Nation and remain fiscally responsible to the same. AACP respectfully offers the following recommendations for your consideration as you undertake your deliberations.

## AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

AACP supports the Friends of AHRQ recommendation of \$350 million for AHRQ programs in fiscal year 2008.

AACP also recommends that the committee direct AHRQ to reestablish the provider-based research network grant program.

The Institute of Medicine (IOM) published two reports in 2006 regarding the reduction of medication use errors and how we can improve medication safety <http://www.nap.edu/catalog/11623.html#toc> and <http://www.nap.edu/catalog/11750.html#toc>. Faculty at colleges and schools of pharmacy are actively engaged in teaching, research, and service to their communities that addresses nearly every one of these report recommendations. Our schools have significant community partnerships that can be furthered enhanced through congressional restoration of the provider-based research network program at AHRQ.

AACP members are active grantees in AHRQ Effective Health Care Program, providing advice on how pharmacy and pharmaceutical technology reduce medical errors and provide for greater patient safety.

## CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The fiscal 2008 funding for the CDC should be increased to \$6.44 billion to restore funding for the preventive health and health services block grants, to restore the health promotion line item to at least fiscal year 2005 levels, and to allow the CDC to continue to focus on keeping our Nation well and healthy. AACP also supports the Friends of the National Center for Health Statistics (NCHS) recommendation that fiscal year 2008 funding be \$117 million.

The curriculum of the Nation's colleges and schools of pharmacy now includes significant focus on public health. Much of this focus is supported by research, information, and programs developed by the Centers for Disease Control and Prevention (CDC). For example, the public health elective offered by the University of Montana School of Pharmacy requires students to purchase the CDC's "Epidemiology and Prevention of Vaccine-Preventable Diseases."

## HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

AACP supports the Friends of HRSA recommendation of at least \$7.65 billion for HRSA in fiscal year 2008.

Many research, education, and service activities at our Nation's colleges and schools are supported by HRSA. Over the last 6 years, HRSA and academic pharmacy have forged a much closer working relationship. This strengthened tie is increasing access to comprehensive pharmacy services, including better utilization of the 340B drug assistance program, for patients served by HRSA grantees and programs. Working more closely with academic pharmacy has also improved the care provided by HRSA supported providers as evidenced in the clinical pharmacy demonstration projects implemented in 18 community health centers across the country. The recognition of U.S. colleges and schools of pharmacy as a resource to the public health safety-net providers can play a significant role in improving programs such as the Ryan White AIDS programs, including the AIDS Drug Assistance Programs, rural health and telemedicine programs, just as it has the community health centers program. We would encourage you to request that HRSA continue to utilize the academy as a resource for program improvement.

As mentioned above, AACP members are actively engaged with many HRSA programs or with HRSA grantees. The following are examples of that engagement.

## COMMUNITY HEALTH CENTERS

AACP recommends that the subcommittee provide \$100 million within the total funding appropriations to CHCs for the development of new comprehensive pharmacy programs. AACP further recommends that \$50 million be made available within the total CHC appropriation for the creation of shared teaching positions between CHCs and colleges and schools of pharmacy to develop and support comprehensive pharmacy services programs. Another option for integrating comprehensive pharmacy services into CHC services would be to place the cost associated with this integration into the base budget of CHC grants.

Relationships between CHCs and academic pharmacists could decrease the gap between the “bench” and the “bedside” in medication management, resulting in more effective, cost-efficient medication therapy. CHCs and academic pharmacy institutions continue to forge an essential link towards improving the health care provided to patients. As the recognized key link in America’s health safety net CHCs should be encouraged to improve or develop comprehensive pharmacy services within their institutions.

## TITLE VII HEALTH PROFESSIONS EDUCATION PROGRAMS

AACP supports the Health Professions and Nursing Education coalition (HPNEC) recommendation of \$300 million for Title VII programs in fiscal year 2008.

For nearly every health profession tracked by the U.S. Bureau of Labor Statistics, high demand will remain for the foreseeable future. Interprofessional education has the potential to help improve health care quality and create greater efficiencies by allowing health professionals to work productively together. NIH has also recognized the growing acceptance of interprofessional research through the “Road Map,” including allowing multiple primary investigators. Colleges and schools of pharmacy are taking a leadership role in the creation of interprofessional approaches to health professions education. Faculty are working across disciplines to develop interprofessional programs and assess their effectiveness through: federally supported programs such as Area Health Education Centers across the country; organizations such as the Institute for Healthcare Improvement and the Association of Academic Health Center; and university level mandates such as that of the University of Minnesota. It is essential that Federal support for interprofessional education be maintained.

## NATIONAL HEALTH SERVICES CORPS

AACP recommends that funding for these programs continue to increase, at least at a rate that takes into account inflation, and waiting lists.

As integral as the CHCs are, they require health professionals to provide the care. While the Title VII programs are essential in creating the education programs that create culturally competent health professionals able to provide team-based, patient-centered care, the NHSC is the program that gets those providers to the community in greatest need. Annual appropriations for the NHSC continue to increase in recognition of the role this program plays in helping to improve access to care in medically underserved and health professions shortage areas.

## OFFICE OF RURAL HEALTH POLICY

AACP recommends that the subcommittee fully restore funding to Rural Health Care Programs. The ORHP supported Rural Health Research Centers grant program is the only source of rural-specific health services research supported by the HHS. Rural Health Research Centers collaborate with schools and colleges of pharmacy in rural health research and dissemination. A paper published by the Upper Midwest Rural Health Center (UMRHC) identified pharmacist staffing, finance, and access to technology as barriers to medication safety in rural hospitals. Through a nationwide survey, the UMRHC found a significant positive relationship between pharmacist staffing and the presence and quality of medication safety initiatives in rural hospitals. Better access to pharmacists in rural hospitals is necessary for reducing medication errors and implementing medication safety systems.

## OFFICE OF TELEHEALTH ADVANCEMENT

AACP recommends that the subcommittee increase the fiscal year 2008 appropriation for telehealth to \$7 million. AACP further recommends that the subcommittee direct the HRSA Office for the Advancement of Telehealth to include development of telepharmacy programs as an explicit grant funding option.

Colleges and schools of pharmacy, including North Dakota State University College of Pharmacy, Washington State University College of Pharmacy, and Texas

Tech University have developed successful telepharmacy programs that are assisting rural providers and their patients improve the management of their medications. The North Dakota Telepharmacy Program has restored, retained, or established pharmacy services to approximately 40,000 rural citizens in North Dakota and Minnesota. The project has not only increased access to medically underserved areas, but has also added approximately \$12 million in economic development to the local rural economies. Duquesne University Mylan School of Pharmacy, located in Pittsburgh, Pennsylvania, has developed and implemented a telepharmacy program that is assisting hospice providers in rural southeastern Pennsylvania, Ohio, West Virginia.

#### NATIONAL INSTITUTES OF HEALTH

AACP, as a member of the Ad Hoc Group for Biomedical Research Funding recommends that fiscal year 2008 NIH funding be increased by 6.7 percent and this same increase be continued for the next 2 years.

AACP would also ask the Congress to commend the NIH for its development of the "PharmD Gateway to NIH" and support efforts for NIH to create opportunities for the development of new clinical pharmacy faculty research.

Our Nation benefits greatly from both intra and extramural NIH research. Our Nation's colleges and schools of pharmacy play an important part in that research agenda. Academic pharmacy supports the NIH Director's Road Map initiative and is especially pleased with recent decisions to allow multiple primary investigators on grants and the support of interdisciplinary research. According to 2006 NIH data, colleges and schools of pharmacy rank fourth after medicine, public health and biomedical engineering in total extramural grant funding. AACP is pleased to recognize the committee for its important role in doubling the NIH budget, however there is growing concern that without continued increases to the NIH budget that work will have been negated. In fiscal year 2006 biomedical research conducted by faculty at U.S. colleges and schools of pharmacy was supported by \$239.7 million. Biomedical research is our Nation's best opportunity for finding cures for disease and reducing the economic burden of illness and chronic illness. The research of academic pharmacy faculty in discovery and application is essential at a time when we grow more dependent on medications to reduce the impact of chronic and acute illness and unexpected threats to our public health.

#### U.S. DEPARTMENT OF EDUCATION

AACP is pleased that the President continues to recognize the importance of higher education to America's global competitiveness. What is of growing concern is that the priorities of the administration frequently come at the expense of existing programs of importance to students attending colleges and schools of pharmacy and the other institutions of higher learning they attend in preparation. The ability of students to be fully prepared to begin pharmacy studies has been heightened through participation in college preparation courses for high school students, summer programs for graduated high school students, and students entering their professional education through programs such as GEAR UP and TRIO. We support the recommendation of the Student Aid Alliance that fiscal year 2008 program funding be \$350 million and \$1 billion respectively.

Academic pharmacy is a leader among the health professions education community in regard to the development of objective, measurable, terminal educational outcomes. Because of growing concern about the assessment of student learning and the value-added aspects of higher education, faculty at our Nation's colleges and schools of pharmacy are ideal resources to work beyond the politics of the Spellings Commission on Higher Education. Academic pharmacy is committed to improving and demonstrating the value of pharmacy education. This commitment led to the creation of AACP's Center for the Advancement of Pharmaceutical Education (CAPE). CAPE has established and recently redefined and expanded educational outcomes. The CAPE outcomes are intended to guide individual institutions in curriculum development. The Accrediting Council on Pharmaceutical Education (ACPE) has adapted these educational outcomes into its recently revised standards and guidelines.

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#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH (AADR) AND THE AMERICAN DENTAL EDUCATION ASSOCIATION (ADEA)

Discoveries stemming from dental research have reduced the burden of oral disease, have led to better oral health for tens of millions of Americans, and have un-

covered important associations between oral and systemic health. Now, dental researchers and educators are poised to make new breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples; and deciphering the complex interactions and causes of oral health care disparities involving social, economic, cultural, environmental, racial/ethnic, and biological factors. Dental research in large part takes place in academic dental institutions where the future oral health workforce receives education and training and provides oral health care that improves the health of the public. Dental research and education are the underpinning of the profession; they enhance the quality of the Nation's oral and overall health. This testimony will cover the following programs and issues:

1. Oral Health Research—The National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR)—
  - a. Elimination of America's most prevalent infectious disease,
  - b. Saliva as a diagnostic tool,
  - c. Understanding factors that cause disparities in oral health,
  - d. Emerging Possibilities from Dental Researchers,
2. Dental Education—Title VII General Dentistry and Pediatric Dentistry and Workforce Training Programs.
3. Access to Dental Care—
  - a. State Children's Health Insurance Program (SCHIP),
  - b. Dental Health Improvement Act,
  - c. Centers for Disease Control and Prevention: Division of Oral Health,
  - d. and Ryan White CARE Act: Dental Reimbursement and Community-based Partnerships Programs

#### INTRODUCTION

The American Association for Dental Research (AADR) represents the oral health research community within the United States, and the American Dental Education Association (ADEA) represents over 120 academic dental institutions as well as all of the educators, researchers, residents and students training at these institutions. Together our organizations represent over 21,000 members in academic dental and dental research institutions throughout the Nation. The joint mission of AADR and ADEA is to enhance the quality and scope of oral health, advance research and increase knowledge for the improvement of oral health, and increase opportunities for scientific innovation. Academic dental institutions play an essential role in conducting research and educating and training the future oral health workforce. Academic dental institutions provide dental care to underserved low-income populations, including individuals covered by Medicaid and the State Children's Health Insurance Program.

We thank the committee for this opportunity to submit testimony regarding the exciting advances in oral health sciences. There are extraordinary opportunities being created through oral health research and education. Herein we submit our fiscal year 2008 budget recommendations for the National Institute of Dental and Craniofacial Research (NIDCR), Title VII Health Professions Education and Training Programs administered by the Health Resources and Services Administration (HRSA), the Dental Health Improvement Act, the State Children's Health Insurance Program (SCHIP), the Centers for Disease Control and Prevention's Oral Health Programs, and the Ryan White CARE Act, HIV/AIDS Dental Reimbursement Program and the Community Based Dental Partnership Program.

#### ORAL HEALTH RESEARCH

Dental research is concerned with the prevention, causes, diagnosis, and treatment of diseases and disorders that affect the teeth, mouth, jaws, and related systemic diseases. Dental health is an important, vital part of health throughout life, and through dental research and education, we can enhance the quality and scope of oral health. Dental research has produced tremendous benefits for the health and well-being of our Nation and the world. Nonetheless, much remains to be done as identified in the Surgeon General's Report of 2000—Oral Health in America<sup>1</sup> and in the 2003—National Call to Action to Promote Oral Health.<sup>2</sup>

<sup>1</sup>Oral Health in America: A Report of the Surgeon General, U.S. Department of Health and Human Services, 2000.

<sup>2</sup>National Call to Action to Promote Oral Health, U.S. Department of Health and Human Services, 2003.

We applaud Congress for demonstrating its overwhelming bipartisan support for NIH by passing the NIH Reform Act of 2006. This reauthorization legislation is an affirmation of the importance of NIH and its vital role in advancing biomedical research to improve the health of the Nation. A renewed national commitment to research and fighting disease, through increased support for the NIH, will allow us to capitalize on new and unprecedented scientific opportunities in oral health research.

#### *Eliminating American's most prevalent infectious disease*

America's most prevalent infectious disease is dental decay (caries)! It is five times more common than asthma and seven times more common than hay fever in school children. Americans spend millions of dollars annually in dental caries treatments and tooth restoration. Over the past 50 years, discoveries stemming from dental research have reduced the burden of dental caries (tooth decay) for many Americans. Now, the burden of the disease, in terms of both extent and severity, has shifted dramatically to a subset of our population. About a quarter of the population now accounts for about 80 percent of the disease burden. Dental caries remains a significant problem for vulnerable populations of children and people who are economically disadvantaged, elderly, chronically ill, or institutionalized.

Dental caries is a chronic, infectious disease process that occurs when a relatively high proportion of bacteria within dental plaque begin to damage tooth structure. Most infectious diseases are treated through medications, not surgery. But, it has been difficult to treat caries this way because our existing diagnostic techniques lack the sensitivity to catch it early enough. New strategies for the prevention, diagnosis, cure and repair of dental caries are being studied and developed by scientists funded through the NIDCR. If caries can be diagnosed before irreversible loss of tooth structure occurs, it can be reversed using a variety of approaches that "remineralize" the tooth. In addition to improved diagnostics, some researchers are working to develop a vaccine to prevent tooth decay, while others use new methods to specifically target and kill the decay-causing bacteria.

#### *Saliva as a Diagnostic Tool*

The development of new diagnostic tests based on the analysis of biomarkers in saliva will allow clinicians to more reliably diagnose disease and monitor health conditions much earlier than is currently possible. Salivary diagnostics is already being used for rapid, non-invasive HIV screening, and saliva-based tests will soon be available for oral cancer screening. Oral cancers and cancer of the larynx are diagnosed in 41,000 individuals accounting for 12,500 deaths per year in the United States. The death rate associated with this cancer is especially high due to delayed diagnosis. Now, scientists funded by the NIDCR have taken a major step forward in using saliva to detect oral cancer. Elevated levels of distinct, cancer-associated molecules in saliva can be used to distinguish between healthy people and those with cancer. Soon, with further research, commercial diagnostic tests will be developed for oral squamous cell carcinoma with the 99+ percent accuracy expected for such tests.

Using saliva may also be possible for diagnosing and monitoring many other systemic health conditions as well as exposure to chemical and biological agents. Early diagnosis could potentially save thousands of lives.

#### *Understanding Factors that Cause Disparities in Oral Health*

Despite tremendous improvements in the Nation's oral health over the past decades, the benefits have not been equally shared by millions of low-income and underserved Americans. High-risk populations, including poor, inner-city, elderly, rural, and groups with special health-care needs, all suffer a disproportionate and debilitating amount of oral disease. Research is needed to identify the factors that determine disparities in oral health and disease. These factors may include proteomic, genetic, environmental, social, and behavioral aspects and how they influence oral health singly or in combination. Translational and clinical research is underway to analyze the prevalence, etiology, and impact of oral conditions on disadvantaged and underserved populations and on the systemic health of these populations. In addition, community- and practice-based disparities research, funded by the NIDCR and the Centers for Disease Control and Prevention's Oral Health Programs, can help to identify and reduce risks, enhance oral health-promoting behaviors, and help integrate research findings directly into oral health care practice.

#### *Other Emerging Exciting Areas in Dental Research*

Looking towards the future—imagine a time when you won't need x-rays to diagnose tooth decay; instead a molecular or electronic probe will do the job. Or imagine

teeth being restored to health, not with fillings, but with simple mineral rinses or bioengineering techniques. This is closer to reality than you might envision!

—*Tissue engineering*.—Tissue engineering holds great potential to repair the ravages of orofacial disease, trauma, war injuries, and birth defects, including the bioengineering of complete, fully functional replacement teeth.

—*Stem cells*.—Isolating stem cells from the ligament around third molars (wisdom teeth) and from human exfoliated deciduous teeth (baby teeth) holds the distinct possibility that one day—in the near future—we may be able to repair dental and craniofacial defects by growing new tissues.

—*System-oral health linkages*.—There is strong evidence of an association between gum (periodontal) disease and systemic events such as cardiovascular disease, diabetes, and adverse pregnancy outcomes. Continued oral health research will provide insight into the prevention and treatment of these and other systemic conditions with links to oral health.

—*Practice Based Research Networks*.—By connecting practitioners with experienced clinical investigators, Practice Based Research Networks (PBRNs) can enhance the utility of clinical research funded by NIDCR by developing data and new techniques that may be immediately relevant to practitioners and their patients.

#### DENTAL EDUCATION

##### *Title VII Programs, Public Health Service Act*

Title VII Education and Training Programs are critical. Support for these programs is essential to expanding existing or establishing new general dentistry and pediatric dentistry residency programs. Title VII general and pediatric dental residency training programs have shown to be effective in increasing access to care and enhancing dentists' expertise and clinical experiences to deliver a wide range of oral health services to a broad patient pool, including geriatric, pediatric, medically compromised patients, and special needs patients. Title VII support increases access to care for Medicaid and SCHIP populations. The value of these programs is underscored by reports of the Advisory Committee on Training in Primary Care Medicine and Dentistry and the Institute of Medicine. Without adequate funding for general dentistry and pediatric dentistry training programs it is anticipated that access to dental care for underserved populations will worsen.

AADR/ADEA also supports the funding requests advanced by National Council for Diversity in the Health Professions for the Health Resources and Services Administration's diversity programs, namely the Scholarship for Disadvantaged Students, Health Careers Opportunity Program, Centers of Excellence, and the Faculty Loan Repayment Program.

#### ACCESS TO DENTAL CARE

##### *State Children's Health Insurance Program*

Reauthorization of the State Children's Health Insurance Program (SCHIP) represents a singular opportunity to move closer to the widely-shared goal of ensuring that all of America's children have health care coverage. Congress has taken a significant step in that direction by signaling in the House and Senate budget resolutions a willingness to provide \$50 billion in new funding for SCHIP reauthorization. Now, relying on the bipartisan support for SCHIP, Congress must work to ensure in a timely manner that SCHIP reauthorization legislation is fully funded and that it includes policies that will support States' efforts to cover more children.

Minority, low-income, and geographically isolated children suffer disproportionately from dental conditions. Dental care tops the list of parent reported unmet needs, with parent reports of unmet dental needs three times as often as medical care and four times that of vision care. For children with special needs, dental care is the most prevalent unmet health care need surpassing mental health, home health, hearing aids and all other services. Despite the magnitude of need, dental coverage has remained an optional benefit in SCHIP. All States have recognized that poor oral health affects children's general health and have opted to provide dental coverage. However, dental coverage is often the first benefit cut when States seek budgetary savings. SCHIP lacks a stable and consistent dental benefit that would provide a comprehensive approach to children's health while reducing costly treatments caused from advanced dental disease. Congress can help stabilize access to oral health care services to underserved children by improving funding for the SCHIP program. It is vital that Congress deliver on its pledge for children's health coverage of \$50 billion in new funds for SCHIP and Medicaid as indicated in the congressional budget resolutions. This level of funding is the minimum amount needed to allow States to sustain their existing SCHIP programs, reach a significant

share of the uninsured children already eligible for SCHIP and Medicaid, and support ongoing State efforts to expand oral health care coverage.

*Dental Health Improvement Act*

The recent reports of tragic deaths of Deamonte Driver, a 12-year-old from Maryland, and Alexander Callender, a 6-year-old from Mississippi, as a result of unmet dental needs tragically illustrate that all children regardless of resources or economic status should have access to oral health care.

Congress provided first-time funding of \$2 million in fiscal year 2006 for the Dental Health Improvement Act, a program established in 2001, to assist States in developing innovative dental workforce programs. The first grants were awarded to States last Fall and are being used for a variety of important initiatives including: increasing hours of operation at clinics caring for underserved populations, recruiting and retaining dentists to work in these clinics, prevention programs including water fluoridation, dental sealants, nutritional counseling, and augmenting the State dental offices to coordinate oral health and access issues.

*Centers for Disease Control and Prevention (CDC) Division of Oral Health*

The Centers for Disease Control and Prevention Oral Health Program expands the coverage of effective prevention programs by building basic capacity of State oral health programs to accurately assess the needs in their State, organize and evaluate prevention programs, develop coalitions, address oral health in State health plans, and effect allocation of resources to the programs. CDC's funding and technical assistance to States is essential to help oral health programs build capacity.

An additional \$4 million over fiscal year 2007 funding of \$11.6 million is necessary so additional States requesting support to improve their capacity to validate, build, and sustain effective preventive interventions to reduce health disparities among their citizens can be funded. Funding for current grantees expires at the end of fiscal year 2007. Twenty-four States have previously applied for these grants but due to limited funding only 12 States were awarded. Increasing CDC funding will help to ensure that all States that apply may be awarded an oral health grant.

*Dental Reimbursement and Community-based Dental Partnership Program*

Congress designated dental care as a "core medical service" when it reauthorized the Ryan White program in 2006. The Dental Reimbursement Program provides access to quality dental care to people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. The Dental Reimbursement Program is a cost-effective Federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. The Community-Based Dental Partnership Program fosters partnerships between dental schools and communities lacking academic dental institutions to ensure access to dental care for HIV/AIDS patients living in those areas.

AADR/ADEA FISCAL YEAR 2008 FUNDING RECOMMENDATIONS SUMMARY

To maintain support for the biomedical research at the NIH AADR/ADEA recommends \$31.3 billion for the National Institutes of Health (NIH) including \$425 million for the National Institute of Dental and Craniofacial Research (NIDCR).

Support the development of innovative dental workforce programs specific to States' needs and increase access to dental care for underserved populations. AADR/ADEA recommends \$10 million for the Dental Health Improvement Act.

Help build basic capacity of State oral health programs. AADR/ADEA recommends \$15.6 million for the CDC Dental Block Grants.

Support education and training of the dental workforce for the future. AADR/ADEA recommends \$450.2 million for the full complement of Title VII health professions programs including:

- \$89 million for the primary care medicine and dentistry cluster to assure:
- \$10 million for General and Pediatric Dental Residency Training.
- \$118 million for the diversity and student assistance cluster:
- \$33.6 million for Centers of Excellence;
- \$35.6 million for Health Careers Opportunity Program;
- \$1.3 million for the Faculty Loan Repayment Program; and
- \$47.1 million for Scholarships for Disadvantaged Students.

Help provide access to oral health care services in SCHIP. AADR/ADEA recommends \$50 billion in new funds for SCHIP and Medicaid.

Assist people with HIV/AIDS, whose immune systems are weakened, to have access to quality dental care. AADR/ADEA recommends \$19 million for of the Ryan

White HIV/AIDS Treatment and Modernization Act, the Dental Reimbursement Program and the Community-based Dental Partnerships Program.

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to present its recommendations on issues related to fiscal year 2008 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP appreciates the work this subcommittee has done in recent years in support of funding for research and services in the area of mental health and aging through the National Institutes of Health (NIH) and the Substance Abuse and Mental Health Services Administration (SAMHSA). Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

#### DEMOGRAPHIC PROJECTIONS AND THE MENTAL DISORDERS OF AGING

With the baby boom generation nearing retirement, the number of older Americans with mental disorders is certain to increase in the future. By the year 2010, there will be approximately 40 million people in the United States over the age of 65. Over 20 percent of those people will experience mental health problems.

Current and projected economic costs of mental disorders alone are staggering. It is estimated that total costs associated with the care of patients with Alzheimer's disease is over \$100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and family burden. These psychiatric symptoms, associated with Alzheimer's disease, can increase the cost of treating these patients by more than 20 percent.

Depression is another example of a common problem among older persons. Of the approximately 32 million Americans who have attained age 65, about 5 million suffer from depression, resulting in increased disability, general health care utilization, and increased risk of suicide. Depression is associated with poorer health outcomes and higher health care costs. Co-morbid depression with other medical conditions affects a greater use and cost of medications as well as increased use of health services (e.g., medical outpatient visits, emergency visits, and hospitalizations). For example, individuals with depression are admitted to the emergency room for hypertension, arthritis, and ulcers at nearly twice the rate of those without depression. Those individuals with depression are more likely to be hospitalized for hypertension, arthritis, and ulcers than those without depression. Those with depression experience almost twice the number of medical visits for hypertension, arthritis and ulcers than those without depression. Finally, the cost of prescriptions and number of prescriptions for hypertension, arthritis, and ulcers were more than twice than those without depression.

Older adults have the highest rate of suicide compared to any other age group. Comprising only 13 percent of the U.S. population, individuals age 65 and older account for 19 percent of all suicides. The suicide rate for those 85 and older is twice the national average. More than half of older persons who commit suicide visited their primary care physician in the prior month—a truly stunning statistic.

#### THE CHALLENGE OF MEETING THE MENTAL HEALTH NEEDS OF THE AGING POPULATION—PROPOSAL FOR IOM STUDY ON MENTAL HEALTH WORKFORCE NEEDS OF OLDER AMERICANS

The Institute of Medicine (IOM) of the National Academy of Sciences is currently undertaking a study of the readiness of the Nation's healthcare workforce to meet the needs of its aging population. IOM has recommended in discussions with AAGP that, because this study will not delve deeply into the composition of the mental health workforce needed to meet future needs of the elderly, a complementary study be undertaken to consider specifically this vital area of concern. This complementary study will focus on the mental health professional workforce that will be needed to

meet the demands of the aging population in this country. IOM is extremely supportive of this proposed study and feel that it would complement their current study on broad health needs of older adults. IOM has advised AAGP that \$1 million would be needed to undertake this complementary mental health study.

In discussions with AAGP, the senior staff of IOM suggested the following language for inclusion in the fiscal year 2008 Labor HHS Appropriations bill:

“The committee provides \$1,000,000 for a study by the Institute of Medicine of the National Academy of Sciences to determine the multi-disciplinary mental health workforce needed to serve older adults. The initiation of this study should be not later than 60 days after the date of enactment of this act, whereby the Secretary of Health and Human Services shall enter into a contract with the Institute of Medicine to conduct a thorough analysis of the forces that shape the mental health care workforce for older adults, including education, training, modes of practice, and reimbursement.”

This proposal for funding for an IOM study on mental health workforce needs of older Americans is supported by the IOM, and AAGP strongly urges its inclusion in the fiscal year 2008 Labor HHS Appropriations bill.

#### NATIONAL INSTITUTE OF MENTAL HEALTH

In his fiscal year 2008 budget, the President again proposed decreased funding for the National Institutes of Health (NIH). This decline in funding would have a devastating impact on the ability of NIH to sustain the ongoing, multi-year research grants that have been initiated in recent years.

AAGP would like to call to the subcommittee's attention the fact that, even in the years in which funding was increased for NIH and NIMH, these increases did not always translate into comparable increases in funding that specifically address problems of older adults. Data supplied to AAGP by NIMH indicates that while extramural research grants by NIMH increased 59 percent during the 5-year period from fiscal year 1995 through fiscal year 2000 (from \$485,140,000 in fiscal year 1995 to \$771,765,000 in fiscal year 2000), NIMH grants for aging research increased at less than half that rate: only 27.2 percent during the same period (from \$46,989,000 to \$59,771,000).

Despite the fact that over the past 6 years Congress, through committee report language, has specifically urged NIMH to increase research grant funding devoted to older adults, this has not occurred. The critical disparity between Federally funded research on mental health and aging and the projected mental health needs of older adults is continuing. If the mental health research budget for older adults is not substantially increased immediately, progress to reduce mental illness among the growing elderly population will be severely compromised. While many different types of mental and behavioral disorders occur in late life, they are not an inevitable part of the aging process, and continued and expanded research holds the promise of improving the mental health and quality of life for older Americans.

#### CENTER FOR MENTAL HEALTH SERVICES

It is also critical that there be adequate funding for the mental health initiatives under the jurisdiction of the Center for Mental Health Services (CMHS) within SAMHSA. While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. SAMHSA provides funding to State and local mental health departments, which in turn provide community-based mental health services to Americans of all ages, without regard to the ability to pay. AAGP was pleased that the final budgets for the last 5 years have included \$5 million for evidence-based mental health outreach and treatment to the elderly. AAGP worked with members of this subcommittee and its Senate counterpart on this initiative, which is a very important program for addressing the mental health needs of the Nation's senior citizens. However, AAGP is extremely alarmed to see that this program was eliminated in President Bush's fiscal year 2008 budget proposal. Restoring and increasing this mental health outreach and treatment program must be a top priority, as it is the only Federally funded services program dedicated specifically to the mental health care of older adults.

The greatest challenge for the future of mental health care for older Americans is to bridge the gap between scientific knowledge and clinical practice in the community, and to translate research into patient care. Adequate funding for this geriatric mental health services initiative is essential to disseminate and implement evidence-based practices in routine clinical settings across the States. Consequently, we would urge that the \$5 million for mental health outreach and treatment for the

elderly included in the CMHS budget for fiscal year 2007 be increased to \$20 million for fiscal year 2008. Of that \$20 million appropriation, AAGP believes that \$10 million should be allocated to a National Evidence-Based Practices Program, which will disseminate and implement evidence-based mental health practices for older persons in usual care settings in the community. This program will provide the foundation for a longer-term national effort that will have a direct effect on the well-being and mental health of older Americans.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

Despite growing evidence of the need for more geriatric specialists to care for the Nation's elderly population, a critical shortage persists. AAGP appreciates the work of this subcommittee in providing for the restoration of funding for the geriatric health professions programs under Title VII of the Public Health Service Act, which was eliminated for fiscal year 2006. The restoration of this programs has prevented a devastating impact on physician workforce development over the next decade, with would have dangerous consequences for the growing population of older adults who will need access to appropriate specialized care. The administration has again proposed eliminating most Title VII programs, including geriatrics. We urge the subcommittee to fund them at the final fiscal year 2007 level. The geriatric health professions program supports three important initiatives. The Geriatric Faculty Fellowship trains faculty in geriatric medicine, dentistry, and psychiatry. The Geriatric Academic Career Award program encourages newly trained geriatric specialists to move into academic medicine. The Geriatric Education Center (GEC) program provides grants to support collaborative arrangements that provide training in the diagnosis, treatment, and prevention of disease.

#### CONCLUSION

Based on AAGP's assessment of the current need and future challenges of late life mental disorders, we submit the following fiscal year 2008 funding recommendations:

1. An Institute of Medicine study on the future mental health workforce needs for older adults should be funded at \$1 million. This proposed report is fully supported by IOM.
2. The current rate of funding for aging grants at NIMH and CMHS is inadequate and should be increased to at least three times their current funding levels. In addition, the substantial projected increase in mental disorders in our aging population should be reflected in the budget process in terms of dollar amount of grants and absolute number of new grants.
3. To help the country's elderly access necessary mental health care, previous years' funding of \$5 million for evidence-based mental health outreach and treatment for the elderly within CMHS must be increased to \$20 million.
4. Funding for the geriatric health professions program under Title VII of the Public Health Service Act should be continued at fiscal year 2007 levels.

AAGP looks forward to working with the members of this subcommittee and others in Congress to establish geriatric mental health research and services as a priority at appropriate agencies within the Department of Health and Human Services.

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists ("AAI"), a not-for-profit professional society representing more than 6,500 of the world's leading experts on the immune system, appreciates having this opportunity to submit testimony regarding fiscal year 2008 funding for the National Institutes of Health (NIH). The NIH budget is of great concern to our members—research scientists and physicians who work in academia, government, and industry—many of whom depend on NIH funding to support their work.<sup>1</sup> With approximately 83 percent of NIH's \$28.9 billion budget awarded to more than 325,000 scientists throughout the United States and around the world, NIH's funding level drives not only the advancement of immuno-logical and biomedical research, but also the economic activity that fuels local and national economies.<sup>2</sup>

<sup>1</sup>The majority of AAI members are medical school and university professors and researchers who receive research grants from NIH, and in particular from the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), and the National Institute on Aging (NIA).

<sup>2</sup>NIH funding "supports peer-reviewed . . . research at more than 3,000 universities, medical schools, hospitals, and research institutions throughout the 50 States and over-

## WHY IMMUNOLOGY?

Basic research on the immune system provides a foundation for the discovery of ways to prevent, treat, and cure disease through the development of diagnostics, vaccines, and therapeutics.<sup>3</sup> Immunologists use animal models to test theories about immune system function and treatments;<sup>4</sup> if successful, treatments are then tested on human subjects through clinical trials before being approved for use by the Food and Drug Administration (“FDA”) and made available to the general population.

Immunological research focuses on many of the diseases that most threaten life and health: infectious diseases like HIV/AIDS, influenza and avian flu, and malaria; and chronic diseases, like diabetes, cancer, and autoimmune diseases. In recent years, immunologists have also been studying the immune response to natural infectious organisms that may be modified for use as agents of bioterrorism, including plague, smallpox, and anthrax. As described below, this crucial work is already bearing fruit.

## RECENT SCIENTIFIC DISCOVERIES: BLOCKBUSTERS AND HOPE

The past year has brought tremendous advances in vaccine development, with promising results in preliminary clinical trials of a vaccine for HIV/AIDS. The vaccine has been shown to be safe and to stimulate cellular immune responses against HIV in more than half of the subjects. Scientists have also discovered that the chickenpox vaccine can be given to adults in order to prevent the occurrence of painful shingles in later years. The hallmark of recent vaccine research was the final FDA approval of the first vaccine against cancer, a vaccine for HPV (Human Papillomavirus). HPV infects over 8 percent of women aged 15–50 and can cause cervical cancer; the new vaccine is efficacious both in preventing primary infection and importantly, in reducing the incidence of cervical cancer.

Immunologists have also made novel insights into understanding “innate” or “natural” immune responses (those that do not require immunization or prior exposure) and the role of soluble factors in inflammation; this has helped scientists discover what appears to have made the 1918 influenza strain so deadly. This discovery may lead to more effective life-saving treatments for influenza patients and will also have broader implications for diseases caused by pandemic influenza, other viruses and bacteria. This and other such advances depend on substantial, reliable, and sustained public investment in basic immunological research.

## BUT THE NIH BUDGET HAS GONE DOWN, THREATENING ONGOING PROGRESS

AAI is very grateful to this subcommittee and the Congress for its successful bipartisan effort to double the NIH budget from fiscal year 1999 to fiscal year 2003. This unprecedented commitment by the Federal Government to biomedical research allowed scientists to grow the research enterprise and train new young investigators. Researchers had begun to capitalize on many important advances, leading to increased translational and clinical applications. Unfortunately, this momentum has already been hampered by sub-inflationary budget increases since fiscal year 2003.<sup>5</sup> As a result, although the NIH budget has slightly increased (from \$27.067 billion in fiscal year 2003 to \$28.931 billion in fiscal year 2007), NIH has already lost about

seas . . . . Additionally, NIH supports 6,000 intramural scientists in its own laboratories.” Fiscal Year 2008 Director’s Budget Request Statement: Fiscal Year 2008 Budget Request, Witness appearing before the House Subcommittee on Labor-HHS-Education Appropriations, Elias A. Zerhouni, M.D., Director, National Institutes of Health (March 6, 2007).

<sup>3</sup>The immune system works by recognizing and attacking “foreign invaders” (i.e., bacteria and viruses) inside the body and by controlling the growth of tumor cells. A healthy immune system can protect its human or animal host from illness or disease either entirely—by attacking and destroying the virus, bacterium, or tumor cell—or partially, resulting in a less serious illness. It will also reject transplanted organs and bone marrow. The immune system can malfunction, allowing the body to attack itself instead of an invader (resulting in an “autoimmune” disease like Type 1 diabetes, multiple sclerosis, or rheumatoid arthritis).

<sup>4</sup>Without animal experimentation, immunologists and other researchers would have to use human subjects, an ethically unacceptable alternative. Despite the clear necessity for animal research, scientists continue to be threatened by people and organizations that oppose such research.

<sup>5</sup>NIH funding increases since the doubling period ended [fiscal year 2004 (3.03 percent), fiscal year 2005 (2.18 percent) and fiscal year 2006 (–.12 percent)] have all been below the “Biomedical Research and Development Price Index (“BRDPI”), a U.S. Department of Commerce annual estimate of the cost of inflation for biomedical research. U.S. Department of Health and Human Services memo dated February 5, 2007: “Biomedical Research and Development Price Index: Fiscal Year 2006 Update and Projections for Fiscal Year 2007–2012.” [http://officeofbudget.od.nih.gov/PDF/BRDPI\\_letter\\_25\\_07.pdf](http://officeofbudget.od.nih.gov/PDF/BRDPI_letter_25_07.pdf) [http://officeofbudget.od.nih.gov/BRDPI\\_2\\_5\\_07.pdf](http://officeofbudget.od.nih.gov/BRDPI_2_5_07.pdf)

8.5 percent in purchasing power since fiscal year 2003. This loss in purchasing power, which would grow to about 13.3 percent if the President's fiscal year 2008 budget were approved,<sup>6</sup> is already having a devastating effect:

1. Key NIH Institutes have already had to drop their RO1 paylines to 10–14 percent, significantly below the approximately 22 percent funded during the doubling. With funding so low, even outstanding grant applications are not being funded on their first submission, forcing even the most successful senior investigators to spend valuable time on revising and resubmitting their applications.

2. The President's budget would provide no inflationary increases for direct, recurring costs in non-competing Research Project Grants (RPGs), for the 3rd straight year.

3. Although the fiscal year 2007 Joint Funding Resolution provides \$91 million to fund 1,500 first-time investigators, the President's fiscal year 2008 budget will either be unable to sustain that promising new effort, or will do so at the expense of funding established investigators.

4. The President's budget would not permit increases in already inadequate stipends and benefits for post-doctoral fellows, whose work is critical to today's established investigators and who will be the principal scientists of tomorrow.

The President's fiscal year 2008 budget would have rapid and long-term adverse repercussions on Americans' health and the national economy: in addition to their terrible human toll, disease and disability cost society trillions of dollars annually in medical care, lost wages and benefits, and lost productivity.<sup>7</sup> The President's budget would also jeopardize the future of the biomedical research enterprise: our brightest young people will be deterred from pursuing biomedical research careers if their chances of receiving an NIH grant, or of being able to sustain a career as an NIH-funded scientist, do not improve. If we are unable to attract and retain the best young minds, the United States will lose more of its senior scientists, as well as its preeminence in medical research, science, and technology, to nations (including India, Singapore, and China) that are already investing heavily in this essential economic sector.

#### AAI RECOMMENDS A 6.7 PERCENT BUDGET INCREASE FOR FISCAL YEAR 2008

AAI urges the subcommittee to increase the NIH budget by 6.7 percent (\$1.9 billion) in fiscal year 2008, to \$30.8 billion. This increase, which is only 3 percent above the projected rate of biomedical research inflation,<sup>8</sup> would begin to restore the loss in purchasing power that has occurred since the NIH budget doubling ended in fiscal year 2003. (Full restoration will require that NIH also receive 6.7 percent increases in fiscal year 2009 and fiscal year 2010.)

#### REAL AND IMMEDIATE THREATS: INFLUENZA AND BIOTERRORISM

Seasonal influenza leads to more than 200,000 hospitalizations and about 36,000 deaths nationwide in an average year. Moreover, an influenza pandemic as serious as the one that occurred in 1918 could result in the illness of almost 90 million Americans and the death of more than 2 million, at a projected cost of \$683 billion.<sup>9</sup> And yet, while one potential pandemic influenza strain, H5N1 (avian influenza), has already killed more than 150 people around the world, the President's fiscal year 2008 NIH budget will permit NIAID to devote only \$223.2 million to influenza (\$11.5 million more than fiscal year 2007). This is an insufficient increase for the agency with primary responsibility for both the scientific research and clinical trials needed to develop vaccines, antiviral drugs, and diagnostic tools to combat both seasonal and pandemic influenza.<sup>10</sup>

AAI is also concerned that the President's fiscal year 2008 NIH budget leaves inadequate funding for biodefense research; the \$1.7 billion allocated represents a net decrease of 0.4 percent (4.1 percent after accounting for projected inflation) from fis-

<sup>6</sup>The President's fiscal year 2008 budget cuts the NIH budget by about \$529 million.

<sup>7</sup>National health expenditures cost \$3.28 trillion in 2006 and are projected to rise to \$4.1 trillion in 2016. U.S. Department of Health and Human Services—Centers for Medicare and Medicaid Services National Health Expenditure Data <http://www.cms.hhs.gov/NationalHealthExpendData/downloads/proj2006.pdf>  
<http://www.cms.hhs.gov/NationalHealthExpendData/downloads/highlights.pdf>

<sup>8</sup>See Footnote 5, *supra*. The BRDPI for fiscal year 2008 is projected to be 3.7 percent.

<sup>9</sup>A report issued by Trust for America's Health ("Pandemic Flu and the Potential for U.S. Economic Recession") predicts that a severe pandemic flu outbreak could result in the second worst recession in the United States since World War II, resulting in a drop in the U.S. Gross Domestic Product of over 5.5 percent.

<sup>10</sup>The Department of Health and Human Services Pandemic Influenza Preparedness and Response Plan gives primary responsibility to NIH, and specifically to NIAID.

cal year 2007. Although the availability of non-recurring construction costs will allow NIAID to devote an additional \$17 million to this research, this inadequate increase is restricting research into the human response to the many natural and man-made pathogens that could be used for nefarious purposes.

AAI strongly believes that the best preparation for a pandemic or bioterrorism is to focus on basic research: for a pandemic, the focus should be on seasonal flu, including building capacity, pursuing new production methods (cell based), and seeking optimized flu vaccines and delivery methods. For bioterrorism, the focus should be on identifying new pathogens, understanding the immune response, and developing tools (including new and more potent vaccines) to protect against the pathogen.<sup>11</sup>

*The new “National Institutes of Health (NIH) Reform Act of 2006”*

The NIH Reform Act of 2006 calls for the establishment of a Division of Portfolio Analysis and Strategic Initiatives to better analyze NIH’s portfolio, provide leadership and coordination for trans-NIH research initiatives (including the NIH “Roadmap for Medical Research”), and fund new trans-NIH initiatives through a “Common Fund”. Although AAI supports this effort to improve NIH analysis and management, AAI urges (1) that the funds allocated to the Common Fund not grow faster than the overall NIH budget, and (2) that all Common Fund awards/grants be awarded through a rigorous peer review process.

*The NIH effort to require all grantees to give NIH author manuscripts*

AAI strongly opposes any effort to require NIH grantees to submit to NIH manuscripts reporting research funded by NIH. Rather, AAI believes that NIH should partner with not-for-profit scientific publishers to provide public access to NIH-funded research results rather than to duplicate, at great cost to NIH and taxpayers, services which are already provided cost-effectively and well by the private sector. AAI urges the subcommittee to require NIH to work with the not-for-profit scientific publishing community to develop a plan to enhance public access that addresses publishers’ concerns, including ensuring journals’ continued ability to provide high quality, independent peer review of NIH-supported research.

*Preserving high quality peer review and ensuring the independence of science*

Millions of lives—as well as the prudent use of taxpayer dollars—depend on the independence of scientists and the willingness of government officials to accept the best, most independent scientific advice available. AAI urges this subcommittee to ensure that funds expended enhance the ability of scientists to provide independent scientific advice (particularly on government advisory panels) and to ensure the vigor of peer review, whether through the NIH peer review system or by supporting the vitality of independent scientific journals which provide independent, expert peer review of taxpayer funded research.

*Ensuring NIH operations and oversight*

AAI is concerned that the President’s fiscal year 2008 budget proposal for Research, Management and Services (RM&S), which supports the management, monitoring, and oversight of all research activities (including NIH’s peer review process), receives an increase of only \$10 million (89 percent). AAI urges the subcommittee to explore whether this sub-inflationary increase will harm NIH’s ability to supervise a portfolio of increasing size and complexity, and to ensure that NIH funds are well and properly spent.

CONCLUSION

AAI greatly appreciates this opportunity to submit testimony and thanks the members of the subcommittee for their strong support for biomedical research, the NIH, and the scientists who devote their lives to preventing, treating, and curing disease.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF MUSEUMS

Chairman Harkin, Senator Specter and distinguished members of the subcommittee, the American Association of Museums (AAM) appreciates the oppor-

<sup>11</sup> The President’s fiscal year 2008 HHS budget requests only \$211 million for the Biomedical Advanced Research and Development Agency (“BARDA”), a new agency established to foster the translation of NIH research into development of medical and bioterrorism countermeasures. AAI is concerned that if BARDA’s budget is inadequate to support its work, NIH may be forced to assume either duties or costs for BARDA.

tunity to submit testimony on the fiscal year 2008 budget for the museum program at the Institute of Museum and Library Services (IMLS). This agency is the primary Federal entity devoted to assisting museums in fulfilling their role as centers for lifelong learning for all Americans. We respectfully request your approval of the administration's budget request of \$39.897 million for grants to museums administered through the Office of Museum Services and the agency's overall budget request of \$271.246 million, which reflects a strong endorsement of the vital public service role museums play in their communities.

The American Association of Museums has been bringing museums together since 1906, helping to develop standards and best practices, gathering and sharing knowledge, and providing advocacy on issues of concern to the entire museum community. AAM currently represents more than 15,000 individual museum professionals and volunteers, 3,000 institutions, and 300 corporate members.

Our Nation's museums are vital community assets. With more than 17,000 institutions collectively holding our Nation's cultural and natural heritage, they serve as a catalyst for our citizens to pursue a greater understanding of the world around them. Every day museums save the memories of our civilization and help create new memories for our visitors. We feed preschoolers' imaginations at children's museums; engage elementary school students in learning about art, history and science; provide teenagers and college students with opportunities to share new found knowledge as tour guides and floor staff; stimulate adult learning with lectures on wide array of topics; and offer grandparents a place to share memories and stories with their grandchildren.

Within your own State, you could easily name with pride the many museums in the communities you serve such as the Dubuque County Historical Society's Mississippi River Museum and Aquarium in Iowa or the Franklin Institute in Philadelphia. The vast majority of museums operate as private nonprofit organizations with nominal government funding unlike other community assets such as schools and libraries. According to our most recent financial survey, nonprofit museums receive approximately 16 percent of their budget from local, State, and the Federal Government. The bulk of their income is derived from private philanthropy in the form of donations, grants and corporate sponsorships and earned income from admission and gift shop sales.

It is critical, therefore, that the Federal Government continue to show leadership by supporting investments to advance America's museums in four important areas—caring for and conserving our collections, improving museum programs and operations, supporting museum professional's development, and conducting research and collecting data to help policymakers, museum trustees and leaders make smart decisions.

#### CARING FOR AND CONSERVING OUR COLLECTIONS

The Heritage Health Index, an example of IMLS-supported research, documented the condition of America's collections held in our Nation's museums, libraries, archives, historical societies and scientific research organizations. It is the first comprehensive survey ever conducted of the condition and preservation needs of our Nation's collections. Through the survey we learned that more than 630 million artifacts—works of art, historic objects, photographs, natural science specimens, books and periodicals—are at risk and require immediate attention and care.

As a result of this study, IMLS has made a commitment to increase public awareness and support for collections care. A national conservation summit will be held here in Washington this spring with future forums planned in four cities across the country to discuss this issue. We are excited at the prospect of increasing attention to this issue, as museums are responsible for the care of hundreds of millions of works of art, artifacts, and scientific specimens, which continue to grow in numbers.

Information related to collections stewardship continues to be the most frequently requested area where AAM members seek guidance on professional standards and best practices. Resources for collections care are often limited, especially in our small and mid-size institutions, due in part to the behind-the-scenes nature of the work. It is not well understood by the public and private funders. We are hopeful that a renewed commitment to and increased public awareness will bring new resources to museums to address the preservation and conservation needs that make public exhibitions possible.

IMLS assists museums with collections issues by providing consultation services through the Conservation and Museum Assessment Programs and financial assistance through the Conservation Project Support program to help ensure some basic safekeeping of museum collections. The demand for this support regularly exceeds the funds available. In fiscal year 2006, IMLS received 144 grant applications and

funded only 40 projects. Recipients matched the nearly \$2.8 million IMLS awarded with an additional \$4.6 million. The grants are helping these museums examine, document, treat, stabilize, and restore their collections. For example, IMLS supported a detailed conservation survey by the Putnam Museum of History and Natural Science in Davenport, Iowa of its approximately 800 lacquered and wood objects in their Japanese and Chinese collections.

#### IMPROVING MUSEUM PROGRAMS AND OPERATIONS

Since its inception, AAM has served as a forum for discussing, developing, disseminating, and measuring museum performance standards. In 1967, President Lyndon B. Johnson asked the U.S. Federal Council on the Arts and Humanities to conduct a study on the status of American museums and recommend ways to support and strengthen them. From this study, *America's Museums: The Belmont Report*, the AAM accreditation program was born. In 1971 AAM first recognized the achievement of 16 museums in meeting the highest standards of the profession. The Accreditation program continues to evolve. Over the past three decades, the program has been a critical tool in advancing the entire museum field, insured transparency and good governance to help museums operate in the best interest of the public.

As our partner in helping museums achieve excellence, IMLS has supported the Museum Assessment Program (MAP). MAP helps museums maintain and improve their operations. Museums participating in the program learn their strengths and weaknesses, receive guidance on how to improve their operations and set institutional priorities. The public benefits by having museums that are striving to improve their operations so they are in a better position to serve them through their public programs and fulfilling their collections stewardship responsibilities.

IMLS also supports museums in their efforts to continue to improve and expand their public service through the Museums for America program. In the program's first 3 years, fiscal year 2004-fiscal year 2006, more than 500 grants totaling \$50.2 million have been awarded. The flexibility of the program has been invaluable to our museums. It allows them to apply for funds to address those high-priority activities that advance their institution's strategic plans. Grants have helped museums deal with a range of issues such as behind-the-scenes collections management projects and staff training, investments in digital technology to broaden public access, planning new public programs, and improving visitor experiences. In fiscal year 2006, the agency received 425 eligible grant applications and only 177 awards could be made.

Among those who were successful, the Children's Museum of Pittsburgh received support for improving its "Real Stuff" exhibits which are at the heart of the museum. The museum is seeking to make changes to areas which have low levels of visitor engagement. Modifications and new exhibits will be based on evaluations from its partnership with the University of Pittsburgh Center for Learning in Out-of-School Environments.

#### SUPPORTING MUSEUM PROFESSIONAL DEVELOPMENT

While museums have long supported the public pursuit of lifelong learning, the staff of museums must also continue to learn. Building the 21st century museum workforce is critical to ensure that museums have both intellectual leadership and financial stability to carry out their mission. The skills required of today's museum directors have changed. In the past, trustees sought individuals with a scholarly knowledge in the area of the museum's collection. Today museum boards are primarily looking for strategic thinkers, excellent communicators, and outstanding fundraisers who have energy, creativity, and an entrepreneurial focus. Museum operations have grown more complex and their leaders need much broader business skills.

Successful museum directors also need capable professionals who have the skills and knowledge to both move the institution forward and attend to the daily operations of running a museum. According to AAM's most recent financial survey, the median number of employees in a museum is 6 full-time and 4 part-time paid staff with 60 volunteers. This includes curators, educators, registrars, accountants, marketing and development professionals with some wearing more than one hat. Unlike our business counterparts, nonprofit museums are not investing time and money to develop and train their staff. Unfortunately, resources for training and career development are scarce. We see this as a looming problem as museums compete with other nonprofits to find and hire future leaders from a shrinking pool of qualified applicants.

In creating the 21st Century Museum Professionals program, IMLS is just beginning to help our field identify strategies for addressing these challenges. In the first year of the program, IMLS received 55 applications but only had the resources to award four grants. There is much work to be done. We urge you to provide the \$2.14 million request by the agency and to consider increasing future investment in workforce development substantially.

#### CONDUCTING RESEARCH AND COLLECTING DATA

It is critical for IMLS to conduct research that assists museum professionals in making critical decisions about their daily operations, demonstrating their public value, ensuring their long-term viability and most effectively meet the needs of the diverse communities they serve. We need basic census data about museums, such as how many museums there are in the United States, how many people work in museums (both paid, professional staff and volunteers), and how many people visit museums annually. A commitment to regular data collection is critical to identifying trends that would inform decision-making by IMLS and the museum community.

For example the 2002 IMLS study, "True Needs, True Partners", about museums serving schools, documented not only the growth in the number of schools, students and teachers served, but also the changing nature of the services provided by museums. This research has helped museum professionals and their school partners understand the evolving nature of their work and documented the growing financial commitment museums have made to public education and how museums have expanded the learning experience for K-12 students.

A number of other topics should be the subject of future research, such as: measuring the social contributions of museums at the national level; studying the skills necessary to be a 21st century museum professional; supporting field research that collects core data, such as financial benchmarks and attendance figures; and examining areas of special interest to segments of the museum field. We need this information and data so that museum leaders and trustees, policy makers at all levels of government and private funders can make informed decisions about the future of our Nation's more than 17,000 museums.

#### CONCLUSION

We recognize that you face difficult choices in allocating resources. Our appeal is to ask you to consider what we lose if we do not continue to invest in our Nation's museums. The public places a great trust in our ability to preserve not only physical artifacts, but more importantly the stories and memories of our people and our Nation. We need museums where you can learn about the past and dream of the future, explore the smallest bugs to the vast expanses of our universe, and experience awe and wonder in the beauty of our world. We cannot do this alone. Working together we can and will continue to inspire future generations of citizens to become thoughtful leaders, creative entrepreneurs, scientists, artists and educators.

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#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

The AANA is the professional association for more than 36,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs are directly involved in delivering 27 million anesthetics given to patients each year in the United States. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, as well as providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and are the sole anesthesia providers in almost 70 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety in the field of anesthesia was bolstered by the Institute of Medicine report that found in 2000, that anesthesia is 50 times safer than 20 years previous. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington, DC, 2000.) Nurse anesthetists continue to set for themselves the most rigorous continuing education and re-certification requirements in the field of anesthesia. Relative anesthesia patient safety outcomes are comparable among nurse anesthetists and anesthesiologists,

with Pine having recently concluded, “the type of anesthesia provider does not affect inpatient surgical mortality.” (Pine, Michael MD et al. Surgical mortality and type of anesthesia provider. Journal of American Association of Nurse Anesthetists. Vol. 71, No. 2, p. 109–116. April 2003.) Even more recently, obstetrical anesthesia, whether provided by Certified Registered Nurse Anesthetists (CRNAs) or anesthesiologists, is extremely safe, and there is no difference in safety between hospitals that use only CRNAs compared with those that use only anesthesiologists, according to the results of a new study published in the January/February issue of Nursing Research (Vol. 56, No. 1, pp. 9–17). In addition, a recent AANA workforce study’s data showed that CRNAs and anesthesiologists are substitutes in the production of surgeries. Through continual improvements in research, education, and practice, nurse anesthetists are vigilant in their efforts to ensure patient safety.

CRNAs provide the lion’s share of the anesthesia care required by our U.S. Armed Forces through active duty and the reserves, from here at home to the leading edge of the field of battle. In May 2003, at the beginning of “Operation Iraqi Freedom” 364 CRNAs were deployed to the Middle East to ensure military medical readiness capabilities. For decades, CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support.

#### IMPORTANCE OF TITLE VIII NURSE ANESTHESIA EDUCATION FUNDING

The nurse anesthesia profession’s chief request of the subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$76 million for advanced education nursing from the Title VIII program. This sustained funding is justified by two facts. First, there is a vacancy rate of nurse anesthetists in the United States impacting people’s healthcare. Second, the Title VIII program, which has been strongly supported by members of this subcommittee in the past, is an effective means to help address the nurse anesthesia workforce demand. This demand for CRNAs is something that the nurse anesthesia profession addresses every day with success, and with the critical assistance of Federal funding through HHS’ Title VIII appropriation.

The administration’s 2008 budget eliminates funding for Advanced Education Nursing. We believe that nursing and nursing education workforce needs are such that this funding must not be eliminated, but preserved and increased for 2008 to meet patient care needs.

The increase in funding for advanced education nursing from \$58 million to \$76 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the United States. Only a limited number of new programs and traineeships can be funded each year at the current funding levels. The program provides for competitive grants and contracts to meet the costs of projects that support the enhancement of advanced nursing education and practice and traineeships for individuals in advanced nursing education programs. This funding is critical to the efforts to meet the nursing workforce needs of Americans who need healthcare.

In 2003, the AANA conducted a nurse anesthesia workforce study that found a 12 percent vacancy rate in hospitals for CRNAs, and a lower vacancy rate in ambulatory surgical centers. The supply has increased in recent years, stimulated by increases in the number of CRNAs trained. However, there is a reasonable question of whether these increases are enough to offset the number of CRNAs intending to retire over the next few years. The retirement of baby boomers, both among patients and CRNAs alike, requires a continuous growth in the number of nurse anesthesia graduates to meet anticipated demand for anesthesia services.

The problem is not that our 105 accredited programs of nurse anesthesia are failing to attract qualified applicants. They have to turn them away by the hundreds, because the capacity of nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors. A qualified applicant to a CRNA program is a bachelor’s educated registered nurse who has spent at least 1 year serving in an acute care healthcare practice environment. Nurse anesthesia educational programs are located all across the country including the following:

State	No. of Accredited Nurse Anesthesia Programs
PA .....	12
FL .....	8
OH .....	5
TX .....	5

State	No. of Accredited Nurse Anesthesia Programs
IL .....	5
NY .....	4
CA .....	3
CT .....	3
MD .....	3
RI .....	2
WI .....	1

Recognizing the importance of nurse anesthetists to quality healthcare, the AANA has been working with the 105 accredited programs of nurse anesthesia to increase the number of qualified graduates. In addition, the AANA has worked with nursing and allied health deans to develop new CRNA programs.

The Council on Certification of Nurse Anesthetists (CCNA) reports that in 1999, our schools produced 948 new graduates. In 2005, that number had increased to 1,790, an 89 percent increase in just 5 years. This growth is expected to continue. The CCNA projects CRNA programs to produce over 2,000 graduates in 2007.

To truly meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to expand. With the help of competitively awarded grants supported by Title VIII funding, the nurse anesthesia profession is making significant progress, expanding both the number of clinical practice sites and the number of graduates.

The AANA is pleased to report that this progress is extremely cost-effective from the standpoint of Federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. As mentioned earlier, the study by Pine et al confirms, "the type of anesthesia provider does not affect inpatient surgical mortality." Yet, for what it costs to educate one anesthesiologist, several CRNAs may be educated to provide the same service with the same optimum level of safety. Nurse anesthesia education represents a significant educational cost/benefit for supporting CRNA educational programs with Federal dollars vs. supporting other models of anesthesia education.

To further demonstrate the effectiveness of the Title VIII investment in nurse anesthesia education, the AANA surveyed its CRNA program directors in 2003 to gauge the impact of the Title VIII funding. Of the eleven schools that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding from 1998 to 2003, the programs indicated an average increase of at least 15 CRNAs graduated per year. They also reported on average more than doubling their number of graduates, who provide care to patients during and following their education. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas. Under both of these circumstances, an increased number of student nurse anesthetists and CRNAs are providing healthcare to the people of medically underserved America.

We believe it is important for the subcommittee to allocate \$4 million for nurse anesthesia education for several reasons. First, as this testimony has documented, the funding is cost-effective and well needed. Second, the Title VIII authorization previously providing such a reserve expired in September 2002. Third, this particular funding is important because nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. Lastly, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

#### TITLE VIII FUNDING FOR STRENGTHENING THE NURSING WORKFORCE

The AANA joins a growing coalition of nursing organizations, including the Americans for Nursing Shortage Relief (ANSR) Alliance and representatives of the nursing community, and others in support of the subcommittee providing a total of \$200 million in fiscal year 2008 for nursing shortage relief through Title VIII. This amount is approximately \$51 million over the fiscal year 2007 level and \$95 million above the President's fiscal year 2008 budget.

Every district in America is familiar with the importance of nursing. The AANA appreciates the support for nurse education funding in fiscal year 2007 and past fiscal years from this subcommittee and from the Congress.

The need for strengthening nurse educational funding to strengthen our healthcare is clear. According to the Office of the Actuary at the Centers for Medicare & Medicaid Services, America spent about \$2 trillion on healthcare in the most

recent year for which the agency had records, the year 2005. About \$342 billion of that was from Medicare outlays. Medicaid spending was \$313 billion. The Congressional Budget Office States that Medicare directs about \$8.7 billion of its outlays to Graduate Medical Education (GME), of which \$2.3 billion was Direct GME. Approximately 99 percent of that educational funding helps to educate physicians and allied health professionals, and about 1 percent is allocated to help educate nurses.

In the interest of patients past and present, particularly those in rural and medically underserved parts of this country, we ask Congress to reject cuts from Federal investments in CRNA and nursing educational funding programs, and to provide these programs the sustained increases required to help ensure Americans get the healthcare that they need and deserve. Quality anesthesia care provided by CRNAs saves lives, promotes quality of life, and makes fiscal sense. This Federal support for nurse education will improve patient access to quality services and strengthen the Nation's healthcare delivery system.

Thank you.

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#### PREPARED STATEMENT OF THE AMERICAN BRAIN COALITION

##### INTRODUCTION

The National Institutes of Health (NIH) is the world's leader in medical discoveries that improve people's health and save lives. NIH-funded scientists investigate ways to prevent, treat, and even cure the complex diseases of the brain. Because there is much work still to be done, the American Brain Coalition writes to ask for your support for biomedical research funding at NIH.

##### WHAT IS THE AMERICAN BRAIN COALITION?

The American Brain Coalition (ABC) is a nonprofit organization that seeks to reduce the burden of brain disorders and advance the understanding of the functions of the brain. The ABC, made up of nearly 50 member organizations, brings together afflicted patients, the families of those that suffer, the caregivers, and the professionals that research and treat diseases of the brain.

The brain is the center of human existence, and the most complex living structure known. As such, there are thousands of brain diseases from Rett Syndrome and autism to dystonia and Parkinson's disease. ABC, unlike any other organization, brings together people affected by all diseases of the brain.

The ABC is working toward the same level of public awareness and support for diseases of the brain that has been achieved by the American Heart Association and the American Cancer Society. Fifty million Americans—our relatives, friends, neighbors, and your constituents—are affected by diseases of the brain. Our goal is to be a united voice for these patients, and to work with Congress to alleviate the burden of brain disease. A large part of that goal involves support for NIH research.

##### THANK YOU FOR PAST SUPPORT

The American Brain Coalition would like to thank the members of this subcommittee for their past support, which resulted in the doubling of NIH budget between 1998 and 2003.

In addition, we are extremely grateful that the fiscal year 2007 Joint Resolution included an additional \$620 million for NIH above the fiscal year 2006 funding level. This additional money will allow NIH to award an extra 500 research grants. It will also create a new program to support innovative, outside-the-box research, as well as to provide grants to first-time investigators.

The doubling of the NIH budget produced advances in the Nation's health. Since 2003, however, many policymakers have mistakenly come to think that NIH "has been taken care of." As a result, NIH has been relatively flat funded since that time.

Despite the doubling of the budget and the many advances in scientific knowledge, there is still much work to be done to uncover the mysteries of the brain. The recent start-stop funding approach has made efficient research planning extremely difficult, has disrupted steady progress, and must be reversed.

##### NIH-FUNDED RESEARCH SUCCESSES

Today, scientists have a greater understanding of how the brain functions due to NIH-funded research. The following are just a few areas where research efforts have improved the health of the American public:

—*Post Traumatic Stress Disorder (PTSD)*.—Experiencing or witnessing a crime, terrorist attack, being a victim of sexual abuse, or military combat can lead to

a form of stress that can last a life-time. Termed, PTSD, the condition afflicts 5.2 million Americans aged 18 to 54 each year. Its social and economic costs can be devastating. Almost half of the Vietnam veterans with PTSD have been arrested or jailed. With the ongoing wars in Iraq and Afghanistan, the incidence of PTSD is rising.

For years it was thought that those who survived or witnessed a trauma should be able to tough it out and move on. But NIH-funded studies helped reveal that PTSD is a serious brain disorder with biological underpinnings. For example, scientists determined that the part of the brain involved in learning, memory, and emotion appears to be smaller in people with PTSD and that levels of some brain chemicals are altered. These changes are believed to be caused by increased stress hormones from a traumatic event and by the constant reliving of the event.

New understanding of the disorder paved the way for use selective serotonin reuptake inhibitors in treating PTSD. Studies funded by NIH found that these drugs ease the symptoms of depression and anxiety and improve the memory of patients with PTSD, helping them better deal with traumatic memories. Talking with a counselor or therapist can also help PTSD victims to cope.

—*Multiple Sclerosis.*—Multiple sclerosis (MS) strikes people during the prime of their lives, right as they are settling into their careers and families. About 400,000 Americans have multiple sclerosis, and every week an estimated 200 more are diagnosed. Multiple sclerosis costs Americans \$9.5 billion in medical care and lost productivity each year.

In multiple sclerosis, the immune system for unknown reasons mistakenly destroys the protective myelin covering around nerves. Without myelin, electrical signals are transmitted more slowly or not at all from the brain to the body, causing weakness, tremors, pain, and loss of feeling.

Fortunately, research funded by the NIH and others over the past two decades has led to many advances that allow physicians to diagnose MS earlier and better track its progress so that treatments can be more effective. Imaging techniques such as magnetic resonance imaging and magnetic resonance spectroscopy provide a window on the brain that allows physicians to better predict relapses and thus plan for patients' care.

In addition to steroids used in the past to reduce the duration and severity of attacks, there are now other drugs like interferon, glatiramer acetate, and mitoxantrone that can decrease disease severity. Studies have shown that these drugs can make relapses less frequent and severe and delay further damage from the disease.

—*Alcoholism.*—Excess consumption of alcohol can ruin a person's health, family life, and career. It also makes the world more dangerous for the rest of society. Many accidents, assaults, and robberies involve alcohol use by the offender. Society also pays a high financial price. Alcohol-related problems cost the country an estimated \$185 billion per year.

Until recently, there were not many options to help keep problem drinkers off alcohol. Fortunately, the outlook is improving steadily with the development of new medications and therapies.

NIH-funded scientists discovered evidence that alcohol acts on several chemical systems in the brain to create its alluring effects. On the basis of these studies, the drug naltrexone—which targets one of these systems, called the opioid system—was approved as a treatment for alcoholism in the mid-1990s. Alcohol's effect on the opioid system is thought to produce the euphoric feelings that make a person want to drink again. Naltrexone can block this reaction and help cut cravings for alcohol in some alcoholic individuals.

Congressional investments in research have lead to significant improvements in patient care.

#### RESEARCH IMPROVES HEALTH AND FUELS THE ECONOMY

Diseases of the nervous system pose a significant public health and economic challenge, affecting nearly one in three Americans at some point in life. Improved health outcomes and positive economic data support the assertion that biomedical research is needed today to improve public health and save money tomorrow.

Research drives innovation and productivity, creates jobs, and fuels local and regional economies. In fiscal year 2003, the University of Wisconsin Madison brought over \$228 million into the State from NIH-funded research.

Not only does research save lives and fuel today's economy, it is also a wise investment in the future. For example, 5 million Americans suffer from Alzheimer's disease today, and the cost of caring for these people is staggering. Medicare ex-

penditures are \$91 billion each year, and the cost to American businesses exceeds \$60 billion annually, including lost productivity of employees who are caregivers. As the baby boom generation ages and the cost of medical services increases, these figures will only grow. Treatments that could delay the onset and progression of the disease by 5 years could save \$50 billion in healthcare costs each year. Research funded by the NIH is critical for the development of such treatments. The cost of investing in NIH today is minor compared to both current and future healthcare costs.

#### PRESIDENT'S BUDGET NEGATIVELY IMPACTS RESEARCH

Mr. Chairman, inflation has eaten into the NIH budget. The NIH now projects the Biomedical Research and Development Price Index (BRDPI) may increase by 3.7 percent for both fiscal year 2007 and fiscal year 2008; 3.6 percent for fiscal year 2009 and 2010; and 3.5 percent for fiscal year 2011 and fiscal year 2012.

Unfortunately, the President's fiscal year 2008 budget request for NIH did not factor in the increases in biomedical research inflation. In fact, his budget proposes to cut funding for the National Institutes of Health by more than a half billion dollars in fiscal year 2008.

#### FISCAL YEAR 2008 RECOMMENDATION

The American Brain Coalition supports a 6.7 percent increase in funding for the National Institutes of Health in fiscal year 2008. Additionally, ABC supports a 6.7 percent increase in funding in per year in fiscal years 2009 and 2010.

This sustained increase is necessary to make-up for lost purchasing power that has occurred in the past 3 years. In addition, it will help the NIH to achieve its broad research goals and provide hope for those people affected with neurological and psychiatric disorders.

Mr. Chairman, thank you for the opportunity to submit testimony before this subcommittee.

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#### PREPARED STATEMENT OF THE AMERICAN COLLEGE OF CARDIOLOGY

The American College of Cardiology (ACC) appreciates the opportunity to provide the subcommittee with recommendations for fiscal year 2008 funding for life-saving cardiovascular research and public education. The ACC is a 34,000 member non-profit professional medical society and teaching institution whose mission is to advocate for quality cardiovascular care through education, research promotion, development and application of standards and guidelines, and to influence health care policy.

#### THE NEED FOR A FEDERAL INVESTMENT IN CARDIOVASCULAR DISEASE RESEARCH

Cardiovascular disease continues to be the leading cause of death for both women and men in the United States, killing more than 870,000 Americans each year. While the number of deaths due to cardiovascular disease is on the decline, more than one in three Americans lives with some form of heart disease. The economic impact of cardiovascular disease on the U.S. health care system continues to grow as the population ages and as the prevalence of it increases, costing the Nation an estimated \$430 billion in 2007 alone due to medical expenses and lost productivity.<sup>1</sup>

The ACC is extremely concerned that the cuts proposed in the administration's fiscal year 2008 budget for many critical health agencies, particularly the National Institutes of Health (NIH), will negatively impact cardiovascular care. The doubling of the NIH budget from 1999 to 2003 resulted in a surge in demand for research grants. In recent years, the combination of inflation and stagnant Federal funding has threatened the laboratories and continuing research of established investigators and, by signaling a lack of Federal commitment to consistent funding, will discourage new investigators and new research initiatives.

The ACC encourages Congress to provide a strong Federal investment in research and public education that addresses cardiovascular disease. Federal research is providing for breakthrough advances that fundamentally change our understanding of the prevention and treatment of cardiovascular disease, leading to better outcomes, decreased costs, and increased quality of life for patients.

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<sup>1</sup>American Heart Association. Heart Disease and Stroke Statistics—2007 Update. Dallas, Texas: American Heart Association; 2007.

## FUTURE CARDIOVASCULAR DISEASE RESEARCH NEEDS

As the health system continues its move toward using performance measurement to foster the delivery of the highest quality of care to patients, the need for meaningful clinical guidelines, from which performance measures are developed, becomes even more critical.

The performance measures that will be used to determine whether patients are receiving the most effective, efficient, and highest quality cardiovascular care are derived from clinical guidelines developed by the ACC and the American Heart Association (AHA). The ACC strives to produce the preeminent medical specialty practice guidelines, with more than 15 guidelines on a range of cardiovascular topics. They are developed through a rigorous, evidence-based methodology employing multiple layers of review and expert interpretation of the evidence on an ongoing, regular basis. Many clinical research questions remain unanswered or understudied, however. In fact, the percent of guideline recommendations that are based on expert opinion rather than clinical data vary by cardiovascular topic from only 20 percent for coronary bypass surgery to over 70 percent for valvular heart disease.

To this end, through its clinical policy development process, the ACC has identified knowledge gaps for cardiovascular disease. These unresolved issues, if addressed, have great potential to impact patient outcomes, costs, and the efficiency of care delivery. The ACC strongly supports and stands committed to assist the National Heart, Lung and Blood Institute (NHLBI) in fulfilling its strategic plan by helping to promote the development and speedy implementation of evidence-based clinical guidelines in a manner that impacts health outcomes. All medicine includes a degree of uncertainty about the ability of a particular procedure, device, or therapy to benefit a patient. Yet, an investment in answering the following scientific questions through the NIH, and in particular the NHLBI, as well as through the Agency for Healthcare Research and Quality (AHRQ), will help to better narrow the target population who can benefit from treatment and therefore increase the efficacy and efficiency of the care delivered.

1. What is the effect of common cardiovascular therapies on elderly populations whose metabolism and kidney function is lower and may not respond to medications in the same way as the younger patients typically included in clinical trials?

2. What is the effect of common cardiovascular therapies on patients with multiple other diseases/conditions?

3. What are the best approaches to increasing patient compliance with existing therapies?

4. What screening and risk models (existing or new) could further define who will benefit from various therapies?

5. What are the optimal management strategies for anticoagulation and antiplatelet agents in heart attack patients, patients with stents, and atrial fibrillation patients to maximize benefit and reduce bleeding risks?

6. What are the best approaches to managing complex but understudied cardiovascular topics such as congenital heart disease and valvular heart disease? Both congenital heart disease and valvular heart disease have become areas of higher research interest as techniques have developed to extend the lives of these patients.

7. What are the risks and benefits of common off-label uses of widely used therapies and procedures, such as drug eluting stents?

8. What are the best catheter-based techniques to increase treatment success and reduce complications for both coronary and cardiac rhythm procedures?

The list of topics above is not exhaustive but provides an overview of some of the general themes of the evidence gaps that exist across the ACC's current guidelines. In addition to specific clinical research topics, the ACC recommends funding to help address two structural issues that could help identify, prioritize, and interpret research findings over the long term:

1. The NHLBI should work with the clinical cardiology community to proactively design clinical trials to address unanswered clinical questions and identify methods that allow for greater comparability among studies. NHLBI should work with ACC and the AHA to develop an evidence model that would drive future research initiatives based on current evidence gaps in the guidelines; and

2. NIH should fund the development of a robust informatics infrastructure across Institutes to process research evidence. Studies should be designed such that their results could be "fed" into a computer model that would provide additional insights for developers of clinical recommendations.

## COLLABORATING TO IMPROVE CARDIOVASCULAR CARE AND OUTCOMES

Facilitating the transfer of new knowledge to health care professionals, patients and the public is an important aspect of Federal research efforts. One example of

NHLBI's success in this area is the launch last year of the new Peripheral Arterial Disease (P.A.D.) national campaign to increase public and health care provider awareness of P.A.D. and its association with other cardiovascular diseases. As the leader in developing the P.A.D. Guidelines, the ACC is proud to collaborate with the NHLBI on the "Stay in Circulation: Take Steps to Learn about P.A.D." campaign. The ACC is promoting this important campaign through our membership and has formed a P.A.D. Guidelines Implementation Task Force that has developed tools—including wall charts, webcasts, and slide sets—to help physicians diagnose and treat the more than 8 million Americans affected by the disease.

NHLBI and AHRQ also have been important supporters of the "D2B: An Alliance for Quality" program. The D2B Alliance is a Guidelines Applied in Practice (GAP) program launched by the ACC to save time and save lives by reducing the door-to-balloon times in U.S. hospitals performing primary percutaneous coronary intervention (PCI) by providing hospitals with key evidence-based strategies and supporting tools needed to begin reducing their D2B times.

Through its Centers for Education and Research on Therapeutics (CERT), AHRQ has been crucial in helping fund research by ACC on its clinical policy development process. The CERT grant provided resources to help ACC better understand and adapt how its guidelines and performance measures are developed and disseminated. It also provided resources to support the development of a framework for ACC to address appropriateness of medical technology. This evaluation of ACC processes for the development of clinical policy has been an essential part of translating research from bench to bedside.

Recently, ACC leadership met with the NHLBI Director and senior staff to discuss opportunities to collaborate on current and future efforts. One initiative identified as a unique opportunity to make a positive impact on health care quality involves enhancing the NHLBI's Center for the Application of Research Discoveries (CARD) through the use of health information technology—namely by drawing on the ACC's substantial expertise, from the National Cardiovascular Data Registry, in developing and operating electronic data registries. Bringing the latest discoveries in cardiovascular care to the bedside is a critical mission of the NHLBI and is shared by the ACC. Sufficient funding from Congress can foster such efforts by the NHLBI and its partners to provide patients with effective cutting-edge care that also holds the promise of reducing health care costs.

#### ACC FUNDING RECOMMENDATIONS

As the subcommittee considers its appropriations for programs within the Department of Health and Human Services, the ACC urges support of the following fiscal year 2008 funding recommendations:

##### *National Institutes of Health*

The ACC, along with the broad medical community, supports an fiscal year 2008 NIH budget of \$30.869 billion that would help get the NIH "back on track." Research conducted through the NIH has resulted in better diagnosis and treatment of cardiovascular disease, thereby improving the quality of life for those living with the disease and lowering the number of deaths attributable to it. Adequate funding through the NIH is necessary for basic, clinical, and translational research that facilitates the delivery of new discoveries to the bedside.

##### *National Heart Lung and Blood Institute*

The ACC recommends \$3.1 billion for the NHLBI in fiscal year 2008 for continuing its critical research into the causes, treatment, and prevention of cardiovascular disease. Congress must maintain its investment in NHLBI to continue the great strides already being made in fighting cardiovascular disease. If accepted without an increase, the administration's budget request for NHLBI would critically impact the institute's ability to fund valuable initiatives and would further harm its ability to attract young investigators.

##### *Agency for Healthcare Research and Quality*

The ACC supports \$350 million for the AHRQ. At a time when great focus is being put on comparative effectiveness research as a means to improve health quality, continuing and increasing the Federal investment in AHRQ health services research is critical.

##### *Centers for Disease Control and Prevention's (CDC) Division for Heart Disease and Stroke Prevention*

The ACC recommends \$55 million for the CDC Division for Heart Disease and Stroke Prevention, whose public education efforts are making strides in the preven-

tion of and early intervention in treating cardiovascular disease—thereby potentially reducing future care costs significantly.

*Health Resources and Services Administration (HRSA) Rural and Community Access to Emergency Defibrillation (AED) Program*

The ACC supports \$8.9 million in fiscal year 2008 for the HRSA Rural and Community AED program, an important initiative that saves lives by placing external defibrillators in public facilities.

The ACC urges Congress to provide a strong fiscal year 2008 investment in the cardiovascular research and education programs described above to continue fostering the great strides being made in the fight against all cardiovascular disease. If you have any questions, please contact Jennifer Brunelle at jbrunell@acc.org or (202) 375-6477.

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PREPARED STATEMENT OF THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

The American College of Obstetricians and Gynecologists (ACOG), representing 51,000 physicians and partners in women's health care, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Harkin, ranking member Specter, and the entire subcommittee for their leadership to continually address maternal and child health care services.

The Nation has made important strides to improve women and children's health over the past several years, and ACOG is grateful to this committee for its commitment to ensure that vital research continues to eliminate disease and to ensure valuable new treatment discoveries are implemented. The NIH has examined and determined many disease pathways, while the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC) have been successful in translating research findings into valuable public health policy solutions. This dedicated commitment to elevate, promote and implement medical research faces an uncertain future at a time when scientists are on the cusp of new cures.

We urge the committee to support a 6.7 percent increase for the National Institutes of Health (NIH), and a 6.7 percent increase for the National Institute of Child Health and Human Development (NICHD) in fiscal year 2008. We also continue to support efforts to secure adequate funds for important public health programs at HRSA (\$7.5 billion) and the CDC (\$10.7 billion including funding for the Agency for Toxic Substances and Disease Registry, and the Vaccines for Children Program).

NATIONAL INSTITUTES OF HEALTH—RESEARCH LEADING THE WAY

*Ob-Gyn Research at the NICHD*

The NICHD conducts research that holds great promise to improve maternal and fetal health and safety. With the support of Congress, the Institute has initiated research addressing the causes of cerebral palsy, gestational diabetes and pre-term birth. However, much more needs to be done to reduce the rates of maternal mortality and morbidity in the United States. More research is needed on such pregnancy-related issues as the impact of chronic conditions during pregnancy, racial and ethnic disparities in maternal mortality and morbidity, drug safety with respect to pregnancy, and preventing unintended pregnancies.

A commitment to research in women's health sheds light on a breadth of issues that save women's lives. Important research examining the following issues must continue:

*Reducing High Risk Pregnancies*

NICHD's Maternal Fetal Medicine Unit Network, working at 14 sites across the United States (University of Alabama, University of Texas-Houston, University of Texas-Southwestern, Wake Forest University, University of North Carolina, Brown University-Women and Infant's Hospital, Columbia University, Drexel University, University of Pittsburgh-Magee Women's Hospital, University of Utah, Northwestern University, Wayne State University, Case Western University, and Ohio State University), will help reduce the risks of cerebral palsy, caesarean deliveries, and gestational diabetes. This Network discovered that progesterone reduces preterm birth by one-third.

*Reducing the Risk of Perinatal HIV Transmission*

In the last 10 years, NICHD research has helped decrease the rate of perinatal HIV transmission from 27 percent to 1.2 percent. This advancement signals the near end to mother-to-child transmission of this deadly disease.

*Reducing the Effects of Pelvic Floor Disorders*

The Institute has made recent advancements in the area of pelvic floor disorders. The NICHD is investigating whether women that have undergone cesarean sections have fewer incidences of pelvic floor disorder than women who have delivered vaginally.

*Reducing the Prevalence of Premature Births*

NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial groups.

*Drug Safety During Pregnancy*

The NICHD recently created the Obstetric and Pediatric Pharmacology Branch to measure drug metabolism during pregnancy.

*Contraceptive Research*

The United States has one of the highest unintended pregnancy rates of the industrialized nations. Of the approximately 6 million pregnancies each year, an estimated one half are unintended. It is critical that women have access to safe and effective contraceptives, to help them time and space their pregnancies. The NICHD conducts valuable research on both male and female contraceptives that can help reduce the number of unintended pregnancies and improve women's health.

*The Challenge of the Future: Attracting New Researchers*

Despite the NICHD's critical advancements, reduced funding has made it difficult for research to continue, largely due to the lack of new investigators. Congressional programs such as the loan repayment program, and the NIH Mentored Research Scientist Development Program for reproductive health, all attract new researchers, but low pay lines make it difficult for the NICHD to maintain them. We urge the committee to significantly increase funding for ob-gyn research at the NICHD to maintain a high level of research innovation and excellence, in turn reducing the incidence of maternal morbidity and mortality and discovering cures for other chronic conditions.

We encourage the committee, too, to realize and fund ob-gyn research possibilities in other Institutes within NIH. While pediatric and ob-gyn research are the two main areas of research in NICHD, ob-gyn research is very centralized in that Institute, with 56.7 percent of all NIH ob-gyn research funding occurring in NICHD in 2005. Pediatrics funding, on the other hand, is diversified throughout many Institutes. While 21.7 percent of pediatrics funding occurs in NICHD, 19 percent is in the National Heart, Lung and Blood Institute (NIHLB), 16 percent is in National Institute of Diabetes and Digestive and Kidney (NIDDK), 13.5 percent in the National Institute of Aging (NIA), and 7 percent is in the National Cancer Institute (NCI). Altogether, pediatrics research at NIH totaled \$520.7 million in 2005, compared with \$156.8 million in ob-gyn research.

The future of women's health, including, reducing preterm labor, ensuring drug safety during pregnancy, and reducing the effects of pelvic floor disorders, depends on research conducted at the NIH. We encourage the committee to increase and expand ob-gyn research funding in NICHD and throughout the National Institutes of Health.

HRSA AND CDC: TURNING RESEARCH INTO PUBLIC HEALTH SOLUTIONS

It is critical that we rapidly transform women's health research findings into public health solutions. The Health Resources and Services Administration (HRSA) has created women and children's health outreach programs based on research conducted on prematurity, high risk pregnancies, gestational diabetes, and a variety of other health issues. The National Fetal Infant Mortality Review and the Provider's Partnership are two examples of the successful programs under the Healthy Start Initiative.

*National Fetal Infant Mortality Review*

The Fetal and Infant Mortality Review (FIMR) is a cooperative Federal agreement between ACOG and the Maternal Child Health Bureau at HRSA. FIMR uses the expertise of ob-gyns and local health departments to find solutions to problems related to infant mortality. In light of the recent increase in the infant mortality rate for 2002, the FIMR program is vital to develop community-specific, culturally appro-

ropriate interventions. Today 220+ local programs in 42 States are implementing FIMR and finding it is a powerful tool to bring communities together to address the underlying problems that negatively affect the infant mortality rate. We urge this committee to recognize the many positive contributions of the FIMR program and ensure it remains a fully funded program within HRSA.

*Title X Family Planning Program*

Since 1970, the Title X Family Planning program at HRSA has provided low income women with timely screenings, education, and contraception. Access to these services can be vital to preventing breast and cervical cancer, sexually transmitted infections (STIs), and unintended pregnancies.

Title X clinics serve more than 5 million low-income women at 4,500 clinics nationwide, helping women plan the number and timing of their pregnancies and stay healthy. Title X clinics are serving increasing numbers of patients without commensurate increases in funding. We urge you to increase funding for this vital program to \$375 million for fiscal year 2008.

*The National Breast and Cervical Cancer Early Detection Program (NBCCEDP)*

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) administered by the CDC is an indispensable health program in helping underserved women gain access to screening programs for early detection of breast and cervical cancers. The NBCCEDP has served over 2.5 million women and provided 5.8 million screening examinations. Early detection and treatment of breast and cervical cancers greatly increase a woman's odds of conquering these diseases. We strongly urge the committee to continue saving women's lives and to prevent cuts to this vital program.

*National Center on Birth Defects and Developmental Disabilities (NCBDDD)*

Birth defects affect about one in every 33 babies born in the United States each year. Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects. According to the CDC, a great opportunity for further improvement lies in prevention strategies that, if implemented prior to conception, would result in further improvement of pregnancy outcomes. A cooperative agreement between the NCBDDD and ACOG has resulted in increased provider knowledge of genetic screening and diagnostic tests, technical guidance on routine preconception care and prenatal genetic screening, and improved access to care for women with disabilities.

Again, we would like to thank the committee for its continued support of inter-agency cooperation to address the multiple factors that affect maternal and child health. We strongly urge this subcommittee to support increased ob-gyn research funding for the NICHD and throughout NIH, and renewed appropriations for the maternal child health programs at the CDC and HRSA. By continuing to translate research done at the NICHD into positive outreach programs such as the Title X program and the NBCCEDP, we can further improve our Nation's overall health.

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PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit testimony on the importance of Federal funding for diabetes programs at the Centers for Disease Control and Prevention (CDC) and diabetes research at the National Institutes of Health (NIH).

As the Nation's leading nonprofit health organization providing diabetes research, information and advocacy, the American Diabetes Association feels strongly that Federal funding for diabetes prevention and research efforts is critical not only for the 20.8 million Americans who currently have diabetes, but also for the 54 million who have a condition known as pre-diabetes.

Diabetes is a serious disease, and is a contributing cause of many of the chronic conditions on which the Federal Government spends the most health care dollars. In 2002, the direct and indirect costs spent solely on diabetes were \$132 billion. In addition, diabetes is a significant cause of heart disease, stroke, and a leading cause of kidney disease, which combine to cost our Nation \$356.7 billion a year. Diabetes is also the leading cause of adult-onset blindness and lower limb amputations.

Between 1990 and 2001 diabetes cases increased 60 percent and they have continued to increase by 8 percent a year. Every 21 seconds, another individual is diagnosed with diabetes. Diabetes is the single most prevalent chronic illness among children. Because of the systemic havoc that diabetes wreaks throughout the body, it is no surprise that the life expectancy of a person with the disease averages 10-15 years less than that of the general population.

As the statistics listed above illustrate, we are facing an epidemic of diabetes in this country, which if left unchecked could have significant health and economic implications for many future generations. Every 24 hours there are: 4,100 individuals diagnosed with diabetes, 230 amputations in people with diabetes, 120 people who enter end-stage kidney disease programs and 55 people who go blind.<sup>1</sup> According to the NIH, approximately 225,000 people died in 2002 from diabetes. Nearly a quarter of a million Americans! Please keep these numbers in mind as you look at the chart below. It tracks the Federal investment in fighting diabetes since fiscal year 2005—a period in which the prevalence of diabetes has grown by approximately 32 percent. In the case of the CDC budget for their Division of Diabetes Translation (DDT), funding has been relatively flat since fiscal year 2003. A change in formula makes it appear that there was a major decrease of 4 percent in fiscal year 2005, when in actuality there was a minor increase.

DDT at CDC	Funding Level	Difference from prior year	Percent increase	
			From prior year	In diabetes
Fiscal year:				
2005 .....	\$63,457	− 2.59	− 4.09	+ 8
2006 .....	63,119	− 9.34	− .54	+ 8
2007 .....	62,806	− .31	− .50	+ 8
2008 administration .....	62,806	.....	.....	+ 8

  

DDK at NIH	Funding level	Difference from prior years	Percent increase	
			From prior year	In diabetes
Fiscal year:				
2005 .....	\$1,864	+ 43	+ 2.31	+ 8
2006 .....	1,855	− 9	− .49	+ 8
2007 .....	1,854	− 1	− .05	+ 8
2008 administration .....	1,858	+ 4	+ .22	+ 8

Diabetes has become the greatest public health crisis of the 21st century. To stem the tide of this epidemic diabetes prevention and outreach efforts must expand, and at the same time scientists and researchers must continue their work towards finding a cure. Therefore, we are requesting:

- A \$20.8 million increase for the CDC's Division of Diabetes Translation (DDT), only one dollar for each American suffering from diabetes. This program was left at flat funding in the recently-passed joint funding resolution, although it had been slated for an increase in both the House and Senate passed bills.
- An 8 percent increase over fiscal year 2007 funding at NIH's National Institute for Diabetes, Digestive and Kidney Diseases (NIDDK), the amount included in last year's NIH Reauthorization package. These funds would make up for previous cuts and allow for the ongoing cost of biomedical inflation, which continues to eat into the purchasing power of research funding.

#### DIABETES INTERVENTIONS AT THE CENTERS FOR DISEASE CONTROL & PREVENTION

The CDC's Division of Diabetes Translation is critical to our national efforts to prevent and manage diabetes because DDT literally translates research into real interventions at the community level. Currently, for every dollar that diabetes costs this country, the Federal Government invests less than one cent to help Americans prevent and manage this deadly disease. This dynamic must be changed. Our request of \$20.8 million will allow these critical programs to expand to more adequately meet the growing demands of the diabetes epidemic.

In 2006, DDT provided support for more than 50 State, and territorial, based Diabetes Prevention and Control Programs (DPCPs) to increase outreach and education, and to reduce the complications associated with diabetes. However, due to funding constraints, DDT is able to provide full support to only 28 States. The remaining 22 States, 8 territories, and the District of Columbia are given no more than partial support. This level of funding, referred to as "capacity building," allows a State to do surveillance, but is not enough for the State to do much—or in some

<sup>1</sup> Frank Vinicor, Associate Director for Public Health Practice at the Centers for Disease Control, qtd. in N.R. Kleinfeld, "Diabetes and Its Awful Toll Quietly Emerges as a Crisis," The New York Times, 9 January 2006.

cases, anything—in the way of intervention. Even more alarming, DDT's current funding level only allows for prevention activities in five States. While we know from clinical trials<sup>2</sup> that the onset of type 2 diabetes can be delayed or prevented in most cases, this dismal funding for primary prevention falls far short of the resources needed to address the 54 million Americans with pre-diabetes.

For those 28 States DDT was able to provide a higher level of support called basic implementation. At this level, States are able to devise and execute community based programs. Without adequately funded diabetes programs and projects in all parts of the country, it will be exceedingly difficult—if not impossible—to control the escalating costs associated with diabetes-associated complications and to stem the epidemic rise in diabetes rates. State DPCPs, when provided with enough funding, are proven to have been extremely successful in helping Americans prevent and manage their diabetes. In the Division of Diabetes Translation Program Review fiscal year 2004, the CDC stated, “The Basic Implementation DPCPs serve as the backbone for our growing primary prevention efforts. These State programs are the key elements to our success in meeting the challenges of controlling and preventing diabetes.”

For example, the Pennsylvania DPCP provides funding to support two of the Commonwealth's eight community-based Diabetes Nurse Consultants which provide information and consultation services to patients and their families, health care providers, schools, nursing homes and countless others in all 67 counties. These programs have demonstrated success in promoting physical activity, weight and blood pressure control, and smoking cessation for those with diabetes. Americans in every State should have access to such quality programs. Unfortunately, States such as Iowa and Mississippi are currently funded at levels that don't allow for basic implementation. The Division's fiscal year 2007 budget of \$63 million had no increase from fiscal year 2006 and the President has requested flat funding again for fiscal year 2008.

In addition to DPCP activities, the CDC's Division of Diabetes Translation conducts other activities to help people currently living with diabetes. To put research into action, CDC works with NIH to jointly sponsor the National Diabetes Education Program (NDEP), which seeks to improve the treatment and outcomes of people with diabetes, promote early detection, and prevent the onset of diabetes. The CDC is also currently working to develop a National Public Health Vision Loss Prevention Program that will investigate the economic burden and strengthen the surveillance and research of this all-to-common complication of diabetes. In addition, CDC funds work at the National Diabetes Laboratory to support scientific studies that will improve the lives of people with diabetes. In fiscal year 2005, the Division of Diabetes Translation alone published 53 manuscripts on the care, prevention, and science of diabetes, including 17 abstracts.

#### DIABETES RESEARCH AT THE NATIONAL INSTITUTES FOR HEALTH

While there is not yet a cure for diabetes, researchers at NIH are working on a variety of projects that represent hope for the millions of individuals with type 1 and type 2 diabetes. The list of advances in treatment and prevention is thankfully a long one, but it is important to understand what has been, and what can be, achieved for Americans with diabetes. For example, the Diabetes Control and Complications Trial (DCCT), a clinical trial of 1,441 people with type 1 diabetes, demonstrated that tight control of blood glucose through intensive insulin therapy could significantly reduce or delay many complications due to diabetes. This landmark finding spurred a shift in the daily management of type 1 diabetes and energized research in the field. Subsequent funding has allowed research to continue on topics like risk factors, genetics, and complications that provide new approaches to improve therapy of diabetes.

Obesity is a strong risk factor for type 2 diabetes, especially in minority populations. Recognizing the growing problem of obesity and its increasing prevalence among youth, the NIDDK is focusing on paths to prevention. One example of this focus is the HEALTHY study, which is led by the NIDDK and co-sponsored by the American Diabetes Association. This study is testing a middle school-based intervention to reduce students' risk factors for type 2 diabetes, such as obesity.

Additionally, based on NIH-funded research, scientists have made great progress in developing methods that slow the onset and progression of kidney disease in peo-

<sup>2</sup>The Diabetes Prevention Program (DPP) was a major clinical trial, or research study, aimed at discovering whether either diet and exercise or the oral diabetes drug metformin (Glucophage) could prevent or delay the onset of type 2 diabetes in people with impaired glucose tolerance.

ple with diabetes, such as employing drugs that are typically used to lower blood pressure. These antihypertensive drugs can slow the progression of kidney disease significantly. Two types of drugs, angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs), have proven effective in slowing the progression of kidney disease.

A generation ago, 20 percent of individuals diagnosed with type 1 diabetes died within 20 years of diagnoses and 30 percent died within 25 years. Thanks to research at NIDDK, patients now use a variety of insulin formulations, including rapid-acting, intermediate acting, long-acting insulin, and even insulin pumps, to control their blood glucose with much better precision. When it comes to diabetes, real-life results from research do not merely represent potential advances; the advances are happening now and they are improving and saving lives.

The Association strongly encourages you to provide at least an 8 percent increase to the NIH to build upon and fulfill this promise of scientific research. Unfortunately, while the death rate due to diabetes has increased by 45 percent since 1987, diabetes research funding has not kept pace. Indeed, from 1987 to 2001, appropriated diabetes funding as a share of the overall NIH budget has dropped by more than 20 percent (from 3.9 percent to 2.9 percent). While Congress had initially begun to address this discrepancy, the fiscal year 2007 Joint Funding Resolution essentially maintained the cuts of recent years, although NIDDK did not have to contribute to the new Common Fund. Still, this does not account for even the cost of biomedical inflation. The Association believes that NIH research and CDC translational programs go hand in hand in the effort to combat the diabetes epidemic.

The Association, and the millions of individuals with diabetes it represents, firmly believes that we could rapidly move toward curing, preventing, and managing this disease by increasing funding for diabetes programs and research at both CDC and NIH. Your leadership is essential to accomplishing this goal. As you are considering fiscal year 2008 funding, we ask you to remember that chronic diseases, including diabetes, account for nearly 70 percent of all health care costs as well as 70 percent of American deaths annually. Unfortunately, less than \$1.25 per person is directed toward public health interventions focused on preventing the debilitating effects associated with chronic diseases, demonstrating that Federal investment in chronic disease prevention remains grossly inadequate. We cannot ignore those Americans who are currently living with diabetes and other diseases.

In closing, the American Diabetes Association strongly urges the subcommittee and the Senate to provide a \$20.8 million increase for the CDC's Division of Diabetes Translation. Providing this funding would be an important step towards empowering the effort fight diabetes at the community and national levels. Additionally, we urge the subcommittee to increase NIH funding by 8 percent, the level that was authorized in the bipartisan NIH Reauthorization legislation that passed both the House and Senate last year by overwhelming margins. These funding levels would allow for an increased commitment to diabetes research.

An important question has been raised, "Where will we be in 10 years?" For diabetes, the answer to that question is truly in your hands. The disease is growing at a rate of 8 percent annually, but the government has not increased the resources to prevent, treat or find a cure for diabetes in over 4 years. In 2002, the United States spent \$132 billion in direct and indirect costs for diabetes. If these trends continue for the next 10 years, the costs—in human life and economics—will be truly unimaginable.

On behalf of the 20.8 million Americans with diabetes—a disease that crosses gender, race, ethnicity and political party; a disease that is among the most costly, debilitating, deadly and prevalent in our Nation; and a disease that is unnecessarily on the rise—I thank you for the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.

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#### PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Over the past 50 years, we have made enormous progress against heart disease, stroke and other forms of cardiovascular disease (CVD). According to the National Institutes of Health, 1.6 million lives have been saved since the 1960s that would have been lost to CVD. Americans can expect to live 4 years longer from a drop in heart disease deaths.

In spite of progress, we have not declared victory, and we may be losing ground. An estimated 80 million American adults suffer from CVD. Despite educational efforts, increased rates of diabetes, obesity and other risk factors may undo four dec-

ades of declining mortality. And, we are often not reaching those at most risk, like those with lower socioeconomic status.

The morbidity and mortality rates still startle. Nearly 2,400 Americans die from CVD each day—an average of one death every 36 seconds. Heart disease and stroke remain the No. 1 and No. 3 killers, respectively, for both men and women in the United States today and two of three men and one of two women will develop CVD during their lifetime.

To make matters worse, a perfect storm is taking shape fueled by demographics. As the baby boomers age, the number of Americans developing CVD will increase radically. CVD can strike at any age, but the odds increase with age. A report estimates that heart disease deaths will increase 130 percent from 2000 and 2050.

Beyond the toll in suffering and death, CVD comes with a steep price tag. It costs Americans an estimated \$432 billion in medical expenses and lost productivity in 2007—more than any other disease. We will soon be facing a CVD crisis of staggering proportions and implications for health care costs and quality of care. We ignore it at our collective peril.

#### BUDGET RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Although progress has been made in the prevention and treatment of CVD, there is still no cure and more Americans than ever are at risk. The most prudent way to address this looming crisis is to simultaneously invest in research, prevention and treatment. Regrettably, the funding levels proposed by the administration in its fiscal year 2008 budget undermine these efforts.

Now is not the time to reduce our investment in programs that prevent and treat America's leading and most costly killer. Solving a problem of this magnitude requires a major public investment. If we fail to take aggressive and deliberate action now—we will pay later in health care expenditures and lives. The American Heart Association's recommendations that follow address this problem in a comprehensive but fiscally responsible way.

#### *Increase Funding for the National Institutes of Health (NIH)*

NIH research has revolutionized patient care and holds the key to a cure for CVD. NIH research also fuels innovation that generates economic growth and preserves our Nation's role as the world leader in the pharmaceutical and biotechnology industries. The President's request is \$511 million below fiscal year 2007 and the gap between the levels achieved during the doubling of the NIH budget and the request, when adjusted for biomedical research inflation, exceeds 13 percent.

*AHA Recommendation.*—AHA advocates for a fiscal year 2008 appropriation of \$30.8 billion for NIH. It represents the first year of a 3-year campaign to get NIH funding "Back on Track." A 6.7 percent funding increase for each of the next 3 years would restore and protect the past investment made by the Congress in doubling the resources of the NIH.

#### *Increase Funding for NIH Heart and Stroke Research: A Proven Investment*

From 1994–2004, death rates from cardiovascular diseases, coronary heart disease and stroke have fallen respectively by 25 percent, 33 percent and 20 percent. Much of this progress can be attributed to NIH heart and stroke research which has improved health outcomes and in some cases, lowered health care costs. Examples of recent NIH research accomplishments include:

- CVD Research a Good Value.*—NIH's cumulative investment in CVD research over the past 30 years has resulted in a 63 percent decrease in heart disease deaths at a projected value of \$1.5 trillion per year from 1970 to 1990 due to increase in life expectancy.
- Stroke Trials Benefit Economy.*—The original NIH tPA trial resulted in a 10-year net reduction in healthcare costs of \$6.47 billion. The Stroke Prevention in Atrial Fibrillation Trial 1 resulted in a 10-year net benefit of \$1.27 billion, with a savings of 35,000 quality-adjusted life years.
- Stroke Rehabilitation.*—Constraint-Induced Movement Therapy, a rehabilitative method involving forced use of a paralyzed arm, can help stroke survivors regain arm function.
- Late Angioplasty No Advantage.*—An international study found that stable heart attack survivors who received angioplasty and stenting three to 28 days after the attack did no better than patients receiving, primarily drug treatment. These findings could reduce unnecessary interventions and lower health care costs.

In spite of these and other successes, NIH heart and stroke research budget remains disproportionately under-funded compared to the disease burden. CVD meets NIH's priority setting criteria (public health needs, scientific quality of research, sci-

entific progress potential, portfolio diversification and adequate infrastructure support), yet only 7 percent of the NIH budget is invested in heart research and a mere 1 percent is devoted to stroke.

#### *Cardiovascular Disease Research*

Relative to the amount needed to keep pace with medical research inflation, proposed funding for cardiovascular research will decline by 15 percent since fiscal year 2003. These limited resources cannot adequately support and expand current activities or allow investments in promising initiatives to aggressively advance the fight against heart disease and stroke—the first and third causes of death among Americans. Additional funds could be used in the following areas:

- Atherosclerosis Prevention Trial.*—Atherosclerosis is a main risk factor for heart disease and stroke. With increased funding, the National Heart, Lung, and Blood Institute (NHLBI) could initiate a clinical trial to determine if reducing low-density lipoprotein cholesterol, so-called “bad” cholesterol, to a level lower than currently recommended, reduces major CVD events in healthy patients at high risk of heart disease and or stroke.
- Systolic Blood Pressure Intervention Trial.*—High blood pressure is a major risk factor for heart disease, heart failure and stroke. Additional funding would allow the NHLBI to conduct a multi-center clinical trial to determine whether reducing systolic blood pressure to a lower level than currently recommended could prevent heart attacks and strokes.
- Preventing Weight Gain in Young Adults.*—With additional resources, NHLBI could support small-scale studies to develop and evaluate promising, innovative practical, cost-effective ways for young adults to reduce their risk for CVD by preventing weight gain.

#### *Stroke Research*

Stroke is the No. 3 killer of Americans and a major cause of permanent disability. In addition to the elderly, stroke also strikes newborns, children and young adults. An estimated 700,000 Americans will suffer a stroke this year, and nearly 150,000 will die. Many of America’s 5.7 million stroke survivors face debilitating physical and mental impairment, emotional distress and huge medical costs; about 1 in 4 survivors are permanently disabled.

As a result of fiscal year 2001 congressional report language, the National Institute of Neurological Disorders and Stroke (NINDS) convened a Stroke Progress Review Group (PRG). Their report provided a long-range strategic plan for stroke research. The PRG was reconvened last year and took stock of interim progress and re-evaluated recommendations for future research. Since the issuance of the initial report, multiple scientific programs have been undertaken; but, more funding is needed to fully implement the strategic plan. The fiscal year 2008 request for NINDS stroke research falls 56 percent short of the strategic plan’s target for that year. Additional funding could be used to conduct stroke research in the following areas:

- Stroke Translational Research.*—Translational studies are vital to providing cutting-edge stroke treatment and prevention. Due to budget shortfalls, the NINDS has been forced to compress its Specialized Programs of Translational Research in Acute Stroke (SPOTRIAS) from the planned 10 extramural centers to the five currently funded. SPOTRIAS researchers facilitate translation of basic research into patient care and evaluate and treat victims rapidly after the onset of stroke symptoms.
- Neurological Emergencies Treatment Trials Network.*—Limited resources will also force the NINDS to scale back its Neurological Emergencies Treatment Trials Network. This initiative is designed to develop a clinical research network of emergency medicine physicians, neurologists and neurosurgeons to develop through clinical trials more and improved treatments for acute neurological emergencies, such as stroke.
- Stroke Education.*—In partnership with CDC, NINDS launched a grassroots program called “Know Stroke in the Community.” It includes enlisting the aid of “Stroke Champions” who teach communities about signs and symptoms. The goal is to shift stroke treatment from supportive care to early brain-saving intervention. But, more funding is needed to teach the public and health providers.

*AHA Recommendation.*—AHA recommends an fiscal year 2008 appropriation of \$2.2 billion for NIH heart research; \$3.1 billion for the NHLBI; \$362 million for NIH stroke research; and \$1.6 billion for the NINDS. These figures represent a 6.7 percent increase over fiscal year 2007—commensurate with the Association’s recommended funding increase for the NIH.

*Increase Funding for the Centers for Disease Control and Prevention (CDC)*

Basic research must be translated into easy-to-understand guidance so people can apply it in their daily lives. Prevention is the best way to protect Americans' health and ease the financial burden of disease. While literature indicates that increased and improved CVD interventions can be highly successful, investigators have also concluded that effective strategies for combating CVD are often not being implemented. A study suggests that not smoking, maintaining a healthy weight, and avoiding diabetes, high blood pressure and high cholesterol may add 10 years to life.

AHA commends Congress for supporting CDC's Division for Heart Disease and Stroke Prevention which funds 33 States to create or implement programs to prevent first and second instances of heart disease and stroke. These state-tailored programs aide collaboration among public and private sectors to help people lower blood pressure and cholesterol, learn signs and symptoms, call 9-1-1, improve emergency response and quality care, and end treatment disparities. Many of these programs have reduced risk, like high blood pressure.

In fiscal year 2007, only 14 States receive funding to implement these prevention programs. The remaining 19 receive funds for planning; which is now largely complete. Because cardiovascular disease is the No. 1 killer in every State, each State needs basic implementation money for this program; however, current funding levels are insufficient for its expansion.

*AHA Recommendation.*—For fiscal year 2008, AHA recommends an appropriation of \$10.7 billion (including funding for ATSDR, and the current funding level for the Vaccines for Children Program) for CDC, with increases targeted for programs within the National Center for Chronic Disease Prevention and Health Promotion. Within that total, we recommend \$64.3 million for the Division for Heart Disease and Stroke Prevention, allowing CDC to: (1) add up to 12 States to the program to conduct state-tailored plans; (2) elevate up to 6 States from planning to program implementation; (3) support the Paul Coverdell National Acute Stroke Registry; (4) start development of a state-based cardiac arrest registry; and (5) explore establishment of a National Heart Disease and Stroke Surveillance Unit to monitor data, identify grave gaps, and offer modifications to existing components to fill the gaps.

*Restore Funding for Rural and Community Access to Emergency Devices (AED) Program*

About 94 percent of cardiac arrest victims die outside of a hospital. Immediate CPR and early intervention using AEDs can more than double a victim's chance of survival. Small, easy-to-use AEDs can shock the heart back into normal rhythm. Placing AEDs in more public settings could save thousands of lives each year. Communities with comprehensive AED programs that include training of anticipated rescuers have achieved survival rates of 40 percent or higher.

The Rural and Community AED Program provides grants to States to train lay rescuers and first responders to use AEDs and buy and place them where sudden cardiac arrests are likely to occur. During the first year of the program, 6,400 AEDs were purchased and 38,800 individuals were trained. AEDs have been placed in schools, faith-based and recreation facilities, nursing homes, and other locations in communities across our Nation. In spite of this success, the Rural and Community AED Program is terminated in the President's fiscal year 2008 budget.

*AHA Recommendation.*—For fiscal year 2008, AHA recommends restoration of HRSA's Rural and Community AED Program to its fiscal year 2005 level of \$8.927 million.

*Increase funding for the Agency for Healthcare Research and Quality (AHRQ)*

AHRQ is a key partner of the public and private health care sectors. AHRQ helps develop evidence-based information needed by consumers, providers, health plans and policymakers to improve health care decision making. Through its Effective Health Care Program, AHRQ supports research focusing on outcomes, comparative clinical effectiveness, and appropriateness of pharmaceuticals, devices and health care services for conditions like ischemic heart disease, stroke, and high blood pressure. The research and comparative effectiveness reviews conducted and funded address issues raised in the Institute of Medicine's Crossing the Quality Chasm.

Their initiative on health information technology is key to our Nation's strategy to bring health care into the 21st century. It includes more than \$166 million in grants. Through these and other projects, AHRQ and its partners help identify challenges to HIT adoption and use, solutions and best practices, and tools that help hospitals and clinicians incorporate HIT.

*AHA Recommendation.*—AHA joins with Friends of AHRQ in advocating for an appropriation of \$350 million for AHRQ, restoring the agency to its fiscal year 2005

level to advance health care quality, cut medical errors and expand availability of health outcomes information.

Although heart disease, stroke and other cardiovascular diseases are largely preventable, they continue to exact a deadly and costly toll. And as baby boomers age, our Nation faces an expanding cardiovascular crisis that threatens to overwhelm us unless significant and meaningful steps are taken. But, adequate funding of research, treatment and prevention programs will save lives and reduce rising health care costs. We urge Congress to consider the Association's recommendations during its deliberations on the fiscal year 2008 budget.

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#### PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

*Summary of Requests.*—Summarized below are the fiscal year 2008 recommendations for the Nation's 34 Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

##### DEPARTMENT OF EDUCATION PROGRAMS

###### A. Higher Education Act Programs

*Strengthening Developing Institutions.*—Section 316 of Title III Part A, specifically supports TCUs through two separate grant programs: (a) basic development grants, and (b) facilities/construction grants designed to address the critical facilities needs at TCUs. The TCUs urge the subcommittee to restore the funding cut proposed in the President's fiscal year 2008 Budget and increase funding to \$32.0 million and that report language be restated clarifying that funds in excess of those needed to support continuation grants or new planning or implementation grants shall be used for facilities, renovation, and construction grants.

*Pell Grants.*—TCUs urge the subcommittee to fund the Pell Grants Program at the highest possible level.

###### B. Perkins Career and Technical Education Programs

The TCUs support \$8.5 million for Sec. 117 of the Carl D. Perkins Career and Technical Education Improvement Act and request language reaffirming that this program remains specific to the two Tribally Controlled Postsecondary Vocational Institutions: United Tribes Technical College and Navajo Technical College. Additionally, TCUs strongly support the Native American Career and Technical Education Program (NACTEP) authorized under Sec. 116 of the act.

###### C. Relevant Title IX Elementary and Secondary Education Act (ESEA) Programs

*Adult and Basic Education.*—Although Federal funding for tribal adult education was eliminated in fiscal year 1996, TCUs continue to offer much needed adult education, GED, remediation and literacy services for American Indians, yet their efforts cannot meet the demand. The TCUs request that the subcommittee direct \$5.0 million of the Adult Education State Grants appropriated funds to make awards to TCUs to support their adult and basic education programs.

*American Indian Teacher and Administrator Corps.*—The American Indian Teacher Corps and the American Indian Administrator Corps offer professional development grants designed to increase the number of American Indian teachers and administrators serving their reservation communities. The TCUs request that the subcommittee support these programs at \$10.0 and \$5.0 million, respectively.

##### DEPARTMENT OF HEALTH & HUMAN SERVICES PROGRAM

###### D. Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF)

Tribal Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs are working to meet the mandate that Head Start teachers earn degrees in Early Childhood Development or a related discipline. The TCUs request that \$5.0 million be designated for the TCU-Head Start partnership program, to ensure the continuation of current TCU programs and the funds necessary for additional TCU-Head Start partnership programs.

Mr. Chairman and members of the subcommittee, on behalf of this Nation's 34 Tribal Colleges and Universities (TCUs), which comprise the American Indian Higher Education Consortium (AIHEC), thank you for the opportunity to share our fiscal year 2008 funding recommendations for programs within the U.S. Department of Education and the U.S. Department of Health and Human Services—Head Start program.

## I. BACKGROUND ON TRIBAL COLLEGES AND UNIVERSITIES:

The vast majority of tribal colleges is accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide much needed high school completion (GED), basic remediation, job training, college preparatory courses, and adult education. Tribal colleges fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public meeting places, and child care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal Colleges and Universities provide access to higher education for American Indians and others living in some of the Nation's most rural and economically depressed areas. The average family income for a student first entering a TCU is \$14,000, which is 27 percent below the Federal poverty threshold for a family of four. In addition to serving their students, TCUs serve their communities through a variety of community outreach programs.

These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs combine traditional teachings with conventional postsecondary curricula. They have developed innovative ways to address the needs of tribal populations and are overcoming long-standing barriers to success in higher education for American Indians. Since the first TCU was established on the Navajo Nation, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to and promoting achievement among students who may otherwise never have known postsecondary education success.

## II. JUSTIFICATIONS

A. *Higher Education Act*

The Higher Education Act Amendments of 1998 created a separate section within Title III, Part A, specifically for the Nation's Tribal Colleges and Universities (Section 316). Programs under Titles III and V of the act support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. Although TCUs, which are truly developing institutions, are providing access to quality higher education opportunities to some of the most rural and impoverished areas of the country, the President's fiscal year 2008 budget proposes a 20 percent cut to the TCU Title III grants program. A clear goal of the Higher Education Act Title III programs is "to improve the academic quality, institutional management, and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to effectively prepare them for the workforce of the 21st Century. The TCUs urge the subcommittee to reject the substantial cut proposed in the President's budget and fund Title III-A section 316 at \$32.0 million in fiscal year 2008, an increase of \$8.2 million over fiscal year 2007 and \$13.5 million over the President's request to afford these developing institutions the resources necessary to address the needs of their historically underserved students and communities. Additionally, we request that report language be restated clarifying that funds in excess of those needed to support continuation grants or new planning or implementation grants shall be used for single year facilities, renovation, and construction grants to ensure TCUs will be able to operate in adequate and safe facilities.

The importance of Pell grants to TCUs students cannot be overstated. U.S. Department of Education figures show that the majority of TCU students receive Pell grants, primarily because student income levels are so low and our students have far less access to other sources of aid than students at State funded and other mainstream institutions. Within the tribal college system, Pell grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. The TCUs urge the subcommittee to fund this critical grants program at the highest possible level.

B. *Carl D. Perkins Career and Technical Education Act*

*Tribally-Controlled Postsecondary Vocational Institutions.*—Section 117 of the Perkins Act provides basic operating funds for two of our member institutions: United

Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. The TCUs urge the subcommittee to fund this program at \$8.5 million.

*Native American Career and Technical Education Program.*—The Native American Career and Technical Education Program (NACTEP) under Sec. 116 of the act reserves 1.25 percent of appropriated funding to support Indian vocational programs. The TCUs strongly urge the subcommittee to continue to support NACTEP, which is vital to the survival of vocational education programs being offered at Tribal Colleges and Universities.

#### *C. Greater Support of Indian Education Programs*

*American Indian Adult and Basic Education (Office of Vocational and Adult Education).*—This program supports adult basic education programs for American Indians offered by TCUs, State and local education agencies, Indian tribes, institutions, and agencies. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those American Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The number of students needing remedial educational programs before embarking on their degree programs is considerable at TCUs. There is a wide need for basic adult educational programs and TCUs need adequate funding to support these essential activities. Tribal colleges respectfully request that the subcommittee direct \$5.0 million of the Adult Education State Grants appropriated funds to make awards to TCUs to help meet the ever increasing demand for basic adult education and remediation program services.

*American Indian Teacher/Administrator Corps (Special Programs for Indian Children).*—American Indians are severely under represented in the teaching and school administrator ranks nationally. These competitive programs are designed to produce new American Indian teachers and school administrators for schools serving American Indian students. These grants support recruitment, training, and in-service professional development programs for Indians to become effective teachers and school administrators and in doing so become excellent role models for Indian children. We believe that the TCUs are the ideal catalysts for these two initiatives because of their current work in this area and the existing articulation agreements they hold with 4-year degree awarding institutions. The TCUs request that the subcommittee support these two programs at \$10.0 million and \$5.0 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES/ADMINISTRATION FOR CHILDREN AND FAMILIES/HEAD START

*Tribal Colleges and Universities (TCU) Head Start Partnership Program.*—The TCU-Head Start Partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. Graduates of these programs help meet the degree mandate for all Head Start program teachers. More importantly, this program has afforded American Indian children Head Start programs of the highest quality. A clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funds made available for the TCU-Head Start Partnership. In fiscal year 1999, the first year of the program, some colleges were awarded 3-year grants, others 5-year grants. In fiscal year 2002, no new grants were funded at all. In fiscal year 2003, funding for eight new TCU grants was made available, but in fiscal year 2004, only two new awards could be made because of the lack of adequate funds. The President's fiscal year 2008 budget includes a total request of \$6,788,571,000 for Head Start Programs. The TCUs request that the subcommittee direct the Head Start Bureau to designate a minimum of \$5.0 million of the \$6.8 billion recommended for the TCU-Head Start Partnership program, to ensure that this critical program can continue and expand so that all TCUs have the opportunity to participate in the TCU-Head Start Partnership program.

#### III. CONCLUSION

Tribal Colleges and Universities provide access to higher education opportunities to many thousands of American Indians, and essential community services and programs to many more. The modest Federal investment in TCUs has already paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. Tribal colleges

need your help if they are to sustain and grow their programs and achieve their missions to serve their students and communities.

Thank you again for this opportunity to present our funding recommendations. We respectfully ask the members of the subcommittee for their continued support of the Nation's Tribal Colleges and Universities and full consideration of our fiscal year 2008 appropriations needs and recommendations.

#### PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

##### SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

	Amount
National Institutes of Health .....	30,537
National Heart, Lung, and Blood Institute .....	3,114
National Cancer Institute .....	5,111
National Institute of Allergy and Infectious Disease .....	4,675
National Institute of Environmental Health Sciences .....	683
National Institute of Nursing Research .....	146
Fogarty International Center .....	70
Centers for Disease Control and Prevention .....	10,700
National Institute for Occupational Safety and Health .....	285
Office on Smoking and Health .....	145
Environmental Health: Asthma Activities .....	70
Tuberculosis Control Programs .....	252
Influenza Pandemic .....	2,652

The American Lung Association is pleased to present our recommendations to the Labor Health and Human Services and Education Appropriations Subcommittee. These programs will make a difference in the lives of millions of Americans who suffer from lung disease.

The American Lung Association is one of the oldest voluntary health organizations in the United States, with a National Office and local associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association today fights lung disease in all its forms.

#### THE TOLL OF LUNG DISEASE

Each year, close to 400,000 Americans die of lung disease. Lung disease is America's number three killer, responsible for one in every six deaths. More than 35 million Americans suffer from a chronic lung disease. Each year lung disease costs the economy an estimated \$157.8 billion. Lung diseases include: asthma, chronic obstructive pulmonary disease, lung cancer, tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

#### CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Chronic Obstructive Pulmonary Disease, or COPD, is a growing health problem. Yet, it remains relatively unknown to most Americans and much of the research community. COPD refers to a group of largely preventable diseases, including emphysema and chronic bronchitis that generally gradually limit the flow of air in the body. COPD is the fourth leading cause of death in the United States and worldwide. In 2004, the annual cost to the Nation for COPD was \$37.2 billion. This includes \$20.9 billion in direct health care expenditures, \$8.9 billion in indirect morbidity costs and \$7.4 billion in indirect mortality costs. Medicare expenses for COPD beneficiaries were nearly 2.5 times that of the expenditures for all other patients.

It has been estimated that 11.4 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2004, 120,104 people in the United States died of COPD. Women have exceeded men in the number of deaths attributable to COPD since 2000. Over the past 30 years, the death rate due to COPD has doubled while the death rates for heart disease, cancer and stroke have decreased by over 50 percent.

Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Research on the genetic susceptibility underlying COPD is making progress. Research is also showing promise for reversing the damage to lung tissue caused by COPD. Despite these promising research leads, the

American Lung Association believes that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world.

The American Lung Association strongly recommends that the NIH and other Federal research programs commit additional resources to COPD research programs. We support increasing the National Heart, Lung and Blood Institute budget to \$3,114 billion. The Lung Association supports the CDC in gathering more information about COPD as part of the National Health and Nutrition Examination Survey, the Behavioral Risk Factor Surveillance System and other health surveys. This information will help public health professionals and researchers understand the disease better and lead to possible control of the disease.

#### TOBACCO USE

Tobacco use is the leading preventable cause of death in the United States, killing more than 438,000 people every year. Smoking is responsible for one in five U.S. deaths. The direct health care and lost productivity costs of tobacco-caused disease and disability are also staggering, an estimated \$167 billion each year.

The CDC's Office on Smoking and Health provides significant technical assistance to States to develop comprehensive and effective tobacco prevention programs, in addition to providing a small, yet essential, amount of Federal assistance directly to State tobacco control and prevention programs. Funds for tobacco prevention at CDC also are used to maintain comprehensive information on smoking and health and to support ongoing research on tobacco-related issues.

We believe Congress should fund the type of youth tobacco prevention programs that science tells us are essential to counter the impact of tobacco company marketing to our kids. The American Lung Association strongly supports a minimum level of \$145 million in fiscal year 2008 funding for the Office on Smoking and Health.

#### ASTHMA

Asthma is a chronic lung disease in which the bronchial tubes become swollen and narrowed, preventing air from getting into or out of the lung. An estimated 32.6 million Americans have ever been diagnosed with asthma by a health professional. Approximately 22.2 million Americans currently have asthma, of which 12.2 million had an asthma attack in 2005. Asthma prevalence rates are almost 12 percent higher among African Americans than whites. Studies also suggest that Puerto Ricans have higher asthma prevalence rates and age-adjusted death rates than all other Hispanic subgroups.

Asthma is expensive. Asthma incurs an estimated annual economic cost of \$16.1 billion to our Nation. Asthma is the third leading cause of hospitalization among children under the age of 15. It is also the number one cause of school absences attributed to chronic conditions. The Federal response to asthma has three components: research, programs and planning. We are making progress on all three fronts but more must be done:

##### *Asthma Research*

Researchers are developing better ways to treat and manage chronic asthma. The NHLBI has shown that using corticosteroids to treat children with mild to moderate asthma is safe and effective. Genetic research is also providing insights into asthma. Researchers in the NHLBI-supported Asthma Clinical Research Network have discovered that a genetic variation determines how well asthma patients will respond to the most common asthma medication, inhaled beta-agonists. This discovery will help physicians better target the drugs they prescribe.

##### *Asthma Programs*

Last year, Congress provided approximately \$31.9 million for the CDC to conduct asthma programs. The American Lung Association recommends that CDC be provided \$70 million in fiscal year 2008 to expand its asthma programs. This funding includes State asthma planning grants, which leverage small amounts of funding into more comprehensive State programs.

##### *Asthma Surveillance*

In addition to public education programs, the CDC has been piloting programs to determine how to establish a nationwide health-tracking system. Congress needs to increase funding to create a nationwide health-tracking system, based on the localized pilots that are underway now.

## LUNG CANCER

An estimated 351,344 Americans are living with lung cancer. During 2007, an estimated 213,380 new cases of lung cancer will be diagnosed. Also, 160,390 Americans will die from lung cancer. Survival rates for lung cancer tend to be much lower than those of most other cancers. Men have higher rates of lung cancer than women. However, over the past 30 years, the lung cancer age-adjusted incidence rate has decreased 9 percent in males compared to an increase of 143 percent in females. Further, African Americans are more likely to develop and die from lung cancer than persons of any other racial group.

Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other Federal research programs commit additional resources to lung cancer research programs. We support increasing the National Cancer Institute budget to \$5.111 billion.

## INFLUENZA

Influenza is a highly contagious viral infection and one of the most severe illnesses of the winter season. It is responsible for an average of 200,000 hospitalizations and 36,000 deaths each year. Further, the emerging threat of a pandemic influenza is looming. Public health experts warn that over half a million Americans could die and over 2.3 million could be hospitalized if a moderately severe strain of a pandemic flu virus hits the United States. To prepare for a potential pandemic, the American Lung Association supports funding the Federal Pandemic Influenza Plan at the recommended level of \$2.652 billion.

## TUBERCULOSIS

Tuberculosis primarily affects the lungs but can also affect other parts of the body. There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2005, there were 14,097 cases of active TB reported in the United States. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB pose a significant threat to the public health of our Nation. Continued support is needed if the United States is going to continue progress toward the elimination of TB. We request that Congress increase funding for tuberculosis programs to \$252 million for fiscal year 2008.

The NIH also has a prominent role to play in the elimination of TB. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances has put the goal of an effective TB vaccine within reach. In addition, the American Lung Association encourages the subcommittee to fully fund the TB vaccine blueprint development effort at the NIAID.

*Fogarty International Center TB Training Programs*

The Fogarty International Center at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area of TB treatment and research. However, we believe TB training grants should not be offered exclusively to institutions that have received AIDS training grants. The TB grants program should be expanded and open to competition from all institutions. The American Lung Association recommends Congress provide \$70 million for FIC to expand the TB training grant program from a supplemental grant to an open competition grant.

## ENVIRONMENTAL HEALTH

The National Institute of Environmental Health Sciences funds vital research on the impact of environmental influence on disease. The American Lung Association supports increasing the appropriation from this subcommittee to \$680 million.

## RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The American Lung Association recommends that the subcommittee provide \$285 million for the National Institute for Occupational Safety and Health (NIOSH) at the CDC.

## CONCLUSION

In conclusion, Mr. Chairman, lung disease is a continuing, growing problem in the United States. It is America's number three killer, responsible for one in seven deaths. The lung disease death rate continues to climb. Mr. Chairman, the level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

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PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS AND THE UNITED NATIONS FOUNDATION

Chairman Harkin, Senator Specter, and members of the subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities.

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF—became one of the spearheading partners of the Measles Initiative, a partnership committed to reducing measles deaths globally. When the Initiative began, the United Nations had set the goal of reducing measles deaths by 50 percent by 2005 compared with 1999 figures. Measles is one of the leading causes of vaccine-preventable death worldwide, and at its outset this partnership committed to meeting that global goal.

Thanks to your leadership in appropriating funds, the international effort to reduce measles deaths has made tremendous progress. In January 2007, in an article published in "The Lancet," WHO announced that this goal was not only reached, but surpassed: global measles deaths had dropped from 873,000 in 1999 to 345,000 in 2005, a reduction of 60 percent. In sub-Saharan Africa, the success was even greater during those years, with measles deaths dropping by 75 percent, from 506,000 to 126,000.

How was this remarkable international public health success achieved? Working closely with host governments, the Measles Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$300 million and provided technical support to host governments in 48 developing countries conducting these vaccination campaigns and improving routine vaccination services. As a result, almost 400 million children in Africa and Asia received measles immunizations, preventing an estimated 2.3 million child deaths.

Nearly all the measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunities that measles vaccination campaigns provide in accessing mothers and young children, and have begun increasingly "integrating" the campaigns with other life-saving health interventions. In addition to measles vaccine, Vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine, and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. The scale of these distributions is immense. For example, more than 18 million ITNs were distributed in vaccination campaigns in the last few years saving more than 378,000 lives. Thus, these campaigns protect young children from both measles and malaria, which kills an African child every 30 seconds. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children's health from a single campaign.

Based on the success in reaching the 2005 measles mortality reduction goal, a bold new global goal has been set: to reduce measles deaths by 90 percent by 2010 compared with 2000 figures. In addition to sustaining the reduction of measles cases and deaths in sub-Saharan Africa, the Initiative will provide funds and technical support to South Asia, where countries with the largest measles burdens are now found. Countries such as Pakistan and India have not yet mounted national measles vaccination campaigns due to competing health priorities and the challenges and costs of vaccinating tens of millions of children. Achieving this new goal will require the continued and expanded support of CDC for the purchase of vaccine and the provision of technical expertise in Africa and Asia.

By controlling measles cases in other countries, U.S. children are also being protected from the disease. A major resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been

strengthened and endemic transmission of measles cases have been eliminated here since 2000. However, importations of measles cases into this country continue to occur each year.

#### ROLE OF CDC IN GLOBAL MEASLES MORTALITY REDUCTION

From fiscal year 2001–2007, Congress provided more than \$250 million in funding to CDC for global measles control activities. These funds were used for the purchase of over 200 million doses of measles vaccine for use in large-scale measles vaccination campaigns in 42 countries in Africa and 6 countries in Asia, and for the provision of technical support to Ministries of Health in those countries. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels.

While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles Initiative, there is no doubt that CDC's support—made possible by the funding appropriated by Congress—was essential in helping achieve the sharp reduction in measles deaths in just 6 years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles Initiative is fortunate in having a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In fiscal year 2007, Congress has appropriated approximately \$43 million to fund CDC for global measles control activities. The American Red Cross and the United Nations Foundation thank Congress for the financial support that has been provided to CDC in the past and this year. We respectfully request an additional \$10 million increase in the fiscal year 2008 funding for CDC's measles control activities so that the gains made to date can continue and the 2010 goal of a 90 percent reduction in measles deaths can be achieved.

The additional funds we are seeking for CDC are critical for:

- Sustaining the great progress in measles mortality reduction in Africa by strengthening measles surveillance and strengthening the delivery of measles vaccine through routine immunization services to protect new birth cohorts;
- Conducting large-scale measles vaccination campaigns in South Asia, thus protecting million of children;
- Conducting nationwide measles vaccination campaigns in countries, such as the Philippines, lacking access to traditional and new funding sources.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. Measles can cause severe complications and death. Your continued support for this initiative helps prevent children from needlessly suffering from this debilitating disease in the United States and abroad.

Thank you for the opportunity to submit testimony.

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#### PREPARED STATEMENT OF THE AMERICAN NEPHROLOGY NURSES' ASSOCIATION

##### INTRODUCTION

On behalf of the American Nephrology Nurses' Association (ANNA), I appreciate having the opportunity to submit written testimony to the Senate Labor, Health, and Human Services (LHHS) Subcommittee regarding funding for nursing and nephrology related programs in fiscal year 2008. ANNA is a professional nursing organization of more than 12,000 registered nurses practicing in nephrology, transplantation, and related therapies. Nephrology nurses use the nursing process to care for patients of all ages who are experiencing, or are at risk for, kidney disease.

ANNA understands that Congress has many concerns and limited resources, but believes kidney disease is a heavy burden on our society that must be addressed. The United States has the highest incidence rate of late stage kidney disease in the

world.<sup>1</sup> The direct economic cost for treating kidney failure is \$20 billion a year in the United States and the number of people diagnosed with kidney failure has doubled each decade for the last 20 years. Because kidney disease imposes such a heavy burden in the United States, we must provide adequate funding for research and prevention programs.

#### KIDNEY DISEASE AND NEPHROLOGY NURSING

Chronic kidney disease (CKD) is the slow, progressive loss of kidney function as a result of abnormalities of the kidney. The National Kidney Foundation estimates that around 20 million Americans have CKD, and another 20 million are at risk. When CKD patients lose 85 percent of kidney function, it is known as end stage renal disease (ESRD).<sup>2</sup> When patients reach ESRD, they must receive replacement therapy either in the form of dialysis or kidney transplant in order to survive. While kidney transplant is a treatment option for many ESRD patients, unfortunately the need for donor organs exceeds the supply, resulting in long waiting times for those who do not have a living donor.

CKD is often undiagnosed until the signs and symptoms related to the loss of kidney function materialize. Risk factors for developing CKD include increasing age, family history and diabetes. The disease is more prevalent in men and people of African American, American Indian, Hispanic, Asian, or Pacific Islander descent.

Since treatment of kidney patients often spans the duration of their lifetime, nephrology nurses must be skilled in offering care for all stages of life and disease progression. Nephrology nurses work in dialysis clinics, hospitals, physician practices, transplant programs, and many other settings.

To ensure that patients receive the best quality care possible, ANNA supports Federal programs and research institutions that address the national nursing shortage and conduct biomedical research into kidney disease and related health problems. Therefore, ANNA respectfully requests the Senate LHHS Appropriations Subcommittee provide increased funding for the following programs:

#### NURSING WORKFORCE AND DEVELOPMENT PROGRAMS AT THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

ANNA supports efforts to resolve the national nursing shortage, including appropriate funding to address the shortage of qualified nursing teaching faculty. Nephrology nursing requires a high level of education and technical expertise, and ANNA is committed to assuring and protecting access to professional nursing care delivered by highly educated, well-trained, and experienced registered nurses for individuals with kidney disease or other disease processes that require replacement therapies.

According to the Department of Health and Human Services, the Nursing Workforce Development programs at HRSA have supported the recruitment, education, and retention of an estimated 36,750 nurses. A report issued by HRSA, *Projected Supply, Demand, and Shortages of Registered Nurses: 2000–2020*, predicts that the nursing shortage is expected to grow by 29 percent by 2020. The HRSA Nursing Workforce Development Programs provide the largest source of Federal funding to address the national nursing shortage, therefore:

ANNA strongly supports the national nursing community's request of \$200 million in fiscal year 2008 funding for Nursing Workforce Development programs at HRSA.

#### NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK)

As the primary professional caretakers of patients with CKD and ESRD, ANNA members support legislative, regulatory, and programmatic efforts that promote prevention and management of chronic kidney disease, including early diagnosis, education and proactive creation of native fistulae for dialysis.

NIDDK supports and conducts research on many serious diseases, including chronic kidney disease and ESRD. Specifically, the National Kidney Disease Education Program (NKDEP) at NIDDK is focused on reducing the overall mortality and morbidity from kidney disease. The programs at NKDEP were created to increase awareness about the seriousness of kidney disease, and the importance of prevention, early diagnosis, and appropriate management of kidney disease.

<sup>1</sup>Sources: National Kidney Disease Education Program, American Nephrology Nurses' Association.

<sup>2</sup>American Nephrology Nurses' Association. (2006). Chronic Kidney Disease Fact Sheet [Brochure]. ANNA Chronic Kidney Disease Special Interest Group: Author.

ANNA encourages Congress to support funding for research into and prevention of kidney disease by providing the maximum possible funding level for NIDDK in fiscal year 2008.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

ANNA understands that research is essential for the advancement of nursing science, and believes new concepts must be developed and tested to sustain the continued growth of the nephrology nursing profession. NINR works to create cost-effective and high-quality health care by testing new nursing science concepts and investigating how to best integrate them into daily practice. NINR has a broad mandate that includes seeking to prevent and delay disease and to ease the symptoms associated with both chronic and acute illnesses. NINR's recent areas of research focus include the following:

- End of life and palliative care in rural areas;
- Research in multi-cultural societies;
- Bio-behavioral methods to improve outcomes research; and
- Increasing health promotion through comprehensive studies.

ANNA respectfully requests \$150 million in funding for NINR in fiscal year 2008 to continue their efforts to address issues related to nursing care for chronic and acute illnesses.

#### CONCLUSION

I appreciate the opportunity to share ANNA's fiscal year 2008 funding priorities for programs designed to address issues relating to kidney disease and provide for a sustainable nursing workforce. Providing \$200 million in fiscal year 2008 funding to the HRSA Nursing Workforce Development programs, \$150 million to NINR and the largest allocation possible for NIDDK will ensure we are providing adequate resources for this fight. ANNA thanks the Senate LHHS Appropriations Subcommittee for their consideration and is happy to serve as a resource regarding these programs or other kidney disease or nursing related issues.

#### PREPARED STATEMENT OF THE AMERICAN OPTOMETRIC ASSOCIATION

The American Optometric Association appreciates the opportunity to submit written testimony to the file of the hearing of the Labor, Health and Human Services, Education and Related Agencies Subcommittee of the Senate Appropriations Committee in support of increased funding the National Eye Institute (NEI), of the National Institutes of Health (NIH).

The American Optometric Association represents over 35,000 practicing Doctors of Optometry across the Nation. As a profession devoted to improving the vision care and health of the public, doctors of optometry examine eyes and the visual system, treat ocular diseases and disorders, and diagnose related systemic conditions.

Doctors of optometry (ODs) are the primary health care professionals for the eye. Optometrists examine, diagnose, treat, and manage diseases, injuries, and disorders of the visual system, the eye, and associated structures, as well as identify related systemic conditions affecting the eye.

- ODs prescribe medications, low vision rehabilitation, vision therapy, spectacle lenses, contact lenses, and perform certain surgical procedures.
- Optometrists counsel their patients regarding surgical and non-surgical options that meet their visual needs related to their occupations, avocations, and lifestyle.
- An optometrist has completed pre-professional undergraduate education in a college or university and 4 years of professional education at a college of optometry, leading to the doctor of optometry (O.D.) degree. Some optometrists complete an optional residency in a specific area of practice.
- Optometrists are eye health care professionals state-licensed to diagnose and treat diseases and disorders of the eye and visual system.

The American Optometric Association (AOA) requests fiscal year 2008 National Institutes of Health (NIH) funding at \$31 billion, or a 6.7 percent increase over fiscal year 2007, to balance the biomedical inflation rate of 3.7 percent and to maintain the momentum of discovery. Although AOA commends the leadership's actions in the 110th Congress to increase fiscal year 2007 NIH funding by \$620 million, this was just an initial step in restoring the NIH's purchasing power, which had declined by more than 13 percent since fiscal year 2005. That power would be eroded even further under the administration's fiscal year 2008 budget proposal. Funding would also be eroded even further under the administration's fiscal year 2008 budget pro-

posals. AOA commends NIH Director, Dr. Elias Zerhouni, who has articulately described his agenda to foster collaborative, cost-effective research and to transform the health care research and delivery paradigm into one that is predictive, preemptive, preventive, and personalized. NIH is the world's premier institution and must be adequately funded so that its research can reduce health care costs, increase productivity, improve quality of life, and ensure our Nation's global competitiveness.

AOA requests that Congress make eye and vision health a top priority by funding the National Eye Institute (NEI) at \$711 million in fiscal year 2008, or a 6.7 percent increase over fiscal year 2007. This level is necessary to fully advance the breakthroughs resulting from NEI's basic and clinical research that are resulting in treatments and therapies to prevent eye disease and restore vision. Vision impairment/eye disease is a major public health problem that is growing and that disproportionately affects the aged and minority populations, costing the United States at least \$68 billion annually in direct and societal costs, let alone the indirect costs of reduced independence and decreased quality of life. Adequately funding the NEI is a cost-effective investment in our Nation's health, as it can delay, save, and prevent expenditures, especially to the Medicare and Medicaid programs.

FUNDING THE NEI AT \$711 MILLION IN FISCAL YEAR 2008 WOULD ENABLE IT TO LEAD TRANS-INSTITUTE VISION RESEARCH THAT MEETS NIH'S GOAL OF PREEMPTIVE, PREDICTIVE, PREVENTIVE, AND PERSONALIZED HEALTH CARE

Funding NEI at \$711 million in fiscal year 2008 represents the judgment of the AOA and its partners in the eye and vision research community as the level necessary to fully advance breakthroughs resulting from NEI's basic and clinical research that are resulting in treatments and therapies to prevent eye disease and restore vision.

—NEI research responds to the NIH's overall major health challenges, as set forth by NIH Director Dr. Zerhouni: an aging population; health disparities; the shift from acute to chronic diseases; and the co-morbid conditions associated with chronic diseases (e.g., diabetic retinopathy as a result of the epidemic of diabetes). In describing the predictive, preemptive, preventive, and personalized approach to health care research, Dr. Zerhouni has also frequently cited NEI-funded research as a tangible example of the value of our Nation's past and future investment in the NIH.

Although NEI's breakthroughs came directly from the past doubling of the NIH budget, their long-term potential to preempt, predict, prevent, and treat disease relies on adequately funding NEI's follow-up research. Unless its funding is increased, the NEI's ability to capitalize on the findings cited above will be seriously jeopardized, resulting in missed opportunities that include:

- Following up on the Age-related Macular Degeneration (AMD) gene discovery by developing diagnostics for early detection and developing promising therapies, as well as to further study the impact of the body's inflammatory response on other degenerative eye diseases.
- Fully investigating the impact of additional, cost-effective dietary supplements in the Age-Related Eye Disease Study (AREDS) study, singly and in combination, to determine if they can demonstrate enhanced protective effects against progression to advanced AMD.

In addition, NEI research into other significant eye disease programs, such as glaucoma and cataract, will be threatened, along with quality of life research programs into low vision and chronic dry eye. This comes at a time when the U.S. Census and NEI-funded epidemiological research (also threatened without adequate funding) both cite significant demographic trends that will increase the public health problem of vision impairment and eye disease.

VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT IS INCREASING HEALTH CARE COSTS, REDUCING PRODUCTIVITY AND DIMINISHING QUALITY OF LIFE

The 2000 U.S. Census reported that more than 119 million people in the United States were age 40 years or older, which is the population most at risk for age-related eye disease. The NEI estimates that, currently, more than 38 million Americans age 40 years and older experience blindness, low vision or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of other chronic, common disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the United States is \$68 billion, this number does not fully quantify the impact of direct health care costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to both the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As a result, Federal funding for the NEI is a vital investment in the health, and vision health, of our Nation, especially our seniors, as the treatments and therapies emerging from research can preserve and restore vision. Adequately funding the NEI can delay, save, and prevent expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

*AOA urges fiscal year 2008 NIH and NEI funding at \$31 billion and \$711 million, respectively*

Of course, vision impairment and eye disease are not limited to the middle-aged and the elderly. Public health experts recommend that children visit an eye care professional in the first year of life—one of the most critical stages of visual development—to identify the potential for eye and vision problems.

In fact, current research shows us that:

- One in 10 children is at risk from undiagnosed eye and vision problems, which, if undetected, could lead to permanent vision impairment, and in rare cases, life-threatening health risks.

- Only 14 percent of children from infancy to age 6 have had a comprehensive eye assessment from an eye care professional.

The NEI has funded several clinical trials in the area of children's vision. The VIP Study (Vision in Preschoolers) evaluated the best screening tests to identify preschool children in need of vision care for amblyopia ("lazy" eye), strabismus (crossed eyes) and significant refractive errors (e.g., nearsightedness or farsightedness). The CLEER Study (Collaborative Longitudinal Evaluation of Ethnicity and Refractive Error) evaluated the role of ethnicity in children's vision conditions. The CIIT Study (Convergence Insufficiency Treatment Trial) is studying the success rates of treatments for convergence insufficiency (eye turns in). The NEI budget should be sufficient to permit funding of grants at a high level in the areas of strabismus, amblyopia and refractive error. Since about 60 percent of Americans have refractive errors requiring eyeglasses or contact lenses, research in the cause and prevention of refractive error should continue.

The value of clinical trials to the public cannot be overestimated. NEI has a remarkable record of scientific breakthroughs attributed to clinical trial research, beginning with studies of diabetic retinopathy in the 1970s. NEI clinical trials involve collaboration with many institutions, health professionals and thousands of patients. Although significant progress has been made, further clinical trial research is needed to determine the causes of refractive error and amblyopia in children and subsequent prevention of visual impairment.

In an effort to encourage early detection and treatment, the American Optometric Association launched in 2005 a national public health initiative to provide no-cost vision assessments for infants. The program is called InfantSEE®, and it's achieving remarkable results for children and their families. Thanks to the more than 7,500 of my colleagues from across the country who have volunteered their time and expertise to make this optometry's most successful vision saving and lifesaving public health initiative, more than 80,000 babies have received a vision assessment at no cost from their local optometrist.

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#### PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

The American Public Health Association (APHA) is the Nation's oldest, largest and most diverse organization of public health professionals in the world, dedicated to protecting all Americans and their communities from preventable, serious health threats and assuring community-based health promotion and disease prevention activities and preventive health services are universally accessible in the United States. We are pleased to submit our views on Federal funding for public health activities in fiscal year 2008.

#### RECOMMENDATIONS FOR FUNDING THE PUBLIC HEALTH SERVICE

APHA's budget recommendation for overall funding for the Public Health Service includes funding for the Centers for Disease Control and Prevention (CDC), the

Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH), as well as agencies outside the subcommittee's jurisdiction—the Food and Drug Administration (FDA) and the Indian Health Service (IHS).

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

APHA believes that Congress should support CDC as an agency—not just the individual programs that it funds. We support a funding level for CDC that enables it to carry out its mission to protect and promote good health and to assure that research findings are translated into effective State and local programs.

In the best professional judgment of APHA, in conjunction with the CDC Coalition—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least \$10.7 billion including sufficient funding to prepare the Nation against a potential influenza pandemic, funding for the Agency for Toxic Substances and Disease Registry and to maintain the current funding level for the Vaccines for Children (VFC) program. This request does not include any additional funding that may be required to expand the mandatory VFC in fiscal year 2008.

APHA appreciates the subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, programs to combat racial, ethnic and geographic disparities in health and health care and environmental health programs at CDC. Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our Nation's public health defense system against emerging and reemerging infectious diseases. With the for an potential onset of an influenza pandemic, in addition to the many other natural and man-made threats, CDC is the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center.

CDC's budget has actually shrunk since 2005 in terms of real dollars—by almost 4 percent. If you add inflation, the cuts are even worse—and these are cuts to the core programs of the agency. The current administration request for fiscal year 2008 is inadequate, with a total cut to core budget categories from fiscal year 2005 to fiscal year 2008 of half a billion dollars. We are moving in the wrong direction, especially in these challenging times when public health is being asked to do more, not less. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

CDC serves as the lead agency for bioterrorism preparedness and must receive sustained support for its preparedness programs in order for our Nation to meet future challenges. APHA supports the proposed increase for anti-terrorism activities at CDC, including the increases for the Strategic National Stockpile. However, we strongly oppose the President's proposed \$125 million cut to the State and local capacity grants. We ask the subcommittee to restore these cuts to ensure that our States and local communities can be prepared in the event of an act of terrorism.

Unfortunately, the President's budget proposes the elimination of some very important CDC programs, like the Preventive Health and Health Services (PHHS) Block Grant. Within an otherwise-categorical funding construct, the PHHS Block Grant is the only source of flexible dollars for States and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. We encourage the subcommittee to restore the cuts and fund the Prevention Block Grant at \$131 million.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), helps States address these serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Please provide adequate funds for this program.

We encourage the subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, State and local level. As with the public health workforce,

the environmental health workforce is declining. Furthermore, the agencies that carry out these services are fragmented and their resources are stretched. These services are the backbone of public health and are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, *E. coli* and lead in drinking water. We encourage the committee to provide at least \$50 million for CDC's Environmental Health Tracking Network.

We also encourage the subcommittee to provide \$50 million to CDC Environmental Health Activities to develop and enhance CDC's capacity to help the Nation prepare for and adapt to the potential health effects of global climate change. This new request for funding would help prepare State and local health department to prepare for the public health impacts of global climate change, allow CDC to fund academic and other institutions in their efforts to research the impacts of climate change on public health and to create a Center of Excellence at CDC to serve as a national resource for health professionals, government leaders and the public on climate change science.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

HRSA programs are designed to give all Americans access to the best available health care services. Through its programs in thousands of communities across the country, HRSA provides a health safety net for medically underserved individuals and families, including more than 45 million Americans who lack health insurance; 50 million Americans who live in neighborhoods where primary health care services are scarce; African American infants, whose infant mortality rate is more than double that of whites; and the estimated 1 to 1.2 million people living with HIV/AIDS. Programs to support the underserved place HRSA on the front lines in erasing our Nation's racial/ethnic and rural/urban disparities in health status. HRSA funding goes where needs exist, in communities all over America. In the best professional judgment of APHA, to respond to this challenge, the agency will require an overall funding level of at least \$7.5 billion for fiscal year 2008.

APHA is gravely concerned about a number of programs that are slated for deep cuts or elimination under the administration's budget proposal. Building on the HRSA programs that were cut or eliminated in the fiscal years 2006 and 2007 appropriations bills, we strongly suggest that this trend is moving our Nation in the wrong direction. We urge the subcommittee to restore funding to HRSA programs that were cut last year, as well as ensure adequate funding for fiscal year 2008 by rejecting the proposed cuts contained in the President's budget.

We express our dismay at the eroding support from the administration for some of HRSA's programs. On top of the \$250 million cut to the agency for fiscal year 2006, the President has proposed another \$321 million overall cut from last year's appropriated level. Under the proposal, total cuts to HRSA since fiscal year 2005 would reach more than \$570 million, a devastating 8 percent cut in 2 years, which has been even more severe for HRSA's core programs from which funding has been diverted to fund other administration priorities. We urge the subcommittee to restore the cuts delivered to these programs in fiscal years 2006 and 2007, and reject the President's proposed cuts for fiscal year 2008. We are again concerned that the HRSA health professions programs under Title VII and VIII of the Public Health Service Act have landed on the chopping block. Today our Nation faces a widening gap between challenges to improve the health of Americans and the capacity of the public health workforce to meet those challenges. These programs help meet the health care delivery needs of the areas in this country with severe health professions shortages, at times serving as the only source of health care in many rural and disadvantaged communities.

We believe the elimination of the Healthy Community Access Program, the Traumatic Brain Injury program, universal newborn hearing screening programs, and the Emergency Medical Services for Children Program, will further undermine the availability of basic health services for those most in need—especially children. The Healthy Community Access Program is an example of communities building partnerships among health care providers to deliver a broader range of health services to their neediest residents. Elimination of the universal newborn hearing screening programs in the administration's budget will leave hearing impairments in infants undetected, negatively impacting speech and language acquisition, academic achievement, and social and emotional development. The proposed elimination of EMSC jeopardizes improvements made to pediatric emergency care, disproportionately affecting children eligible for Medicaid and SCHIP, but not enrolled due to State enrollment limits and budgetary pressures, and therefore frequently use emergency health services.

The Maternal and Child Health Block Grant is also operating for a third year with less funds than in fiscal year 2005, yet with greater needs among pregnant women, infants, and children, particularly those with special health care needs.

We are pleased with the increases proposed by the President for programs under the Ryan White CARE Act, administered by HRSA's HIV/AIDS Bureau. The CARE Act programs are an important safety net, providing an estimated 571,000 people access to services and treatments each year. At a time when the number of new domestic HIV/AIDS cases is increasing, we support increased funding for these programs.

Through its many programs, HRSA helps countless individuals live healthier lives. APHA believes that with adequate resources, HRSA is well positioned to meet these challenges as it continues to provide needed health care to the Nation's most vulnerable citizens. Please restore funds to these important public health programs.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

We request a funding level of \$350 million for the AHRQ for fiscal year 2008. This level of funding is needed for the agency to fully carry out its congressional mandate to improve health care quality, including eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities. The cuts proposed in the administration budget will severely hamper these efforts.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

APHA supports a funding level of \$3.532 billion for SAMHSA for fiscal year 2008. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

APHA supports a funding level of \$30.869 billion for the NIH for fiscal year 2008. The translation of fundamental research conducted at NIH provides some of the basis for community based public health programs that help to prevent and treat disease.

In closing, we emphasize that the public health system requires financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. We ask you to think in a broad and balanced way, leveraging funding whenever possible to provide public health benefits as a matter of routine, rather than emergency.

We thank the subcommittee for the opportunity to present our views on the fiscal year 2008 appropriations for public health service programs.

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### PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

#### INTRODUCTION

The American Society of Nephrology (ASN) is pleased to submit this statement for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education.

The ASN is a professional society of more than 10,000 researchers, physicians, and practitioners committed to the treatment, prevention, and cure of kidney disease. Specifically, the ASN strives to enhance and assist the study and practice of nephrology, to provide a forum for the promulgation of research, and to meet the professional and continuing education needs of its members.

This ASN statement focuses on those issues and programs that most immediately fall under the committee's jurisdiction and assist our members to fulfill their missions. We want to express our strong support for advancing programs supported by the National Institutes of Health (NIH) and Agency for Healthcare Research and Quality (AHRQ). The ASN thanks the subcommittee for its commitment and steadfast support of these programs.

#### KIDNEY DISEASE: A GROWING PUBLIC HEALTH CONCERN

Kidney disease is the ninth leading cause of death in the United States. It is estimated that at least 15 million people have lost 50 percent of their kidney function. Another 20 million more Americans are at increased risk of developing kidney dis-

ease. The culmination of unimpeded progression is end stage renal disease (ESRD), a condition in which patients have permanent kidney failure, affects almost 400,000 Americans and directly causes 50,000 deaths annually. In the past 10 years, the number of patients in the United States with ESRD has almost doubled and it is expected to reach 700,000 by 2015, according to the United States Renal Data System (USRDS). ESRD disproportionately affects minorities. For example, although they constitute approximately 12 percent of the U.S. Population, African Americans comprise 32 percent of the prevalent ESRD population and are nearly four times more likely to develop kidney disease than Caucasians. Native Americans are twice as likely. The elderly are also disproportionately affected. One in four new ESRD patients was 75 or older in 2004. The two major therapies for ESRD are dialysis and kidney transplantation. The number of patients waiting for a kidney transplant increased from 9,452 in 1988 to 60,393 in 2004. Almost 50 percent of kidney transplants are received by people aged 45–64.

#### ECONOMIC COSTS

Although no dollar amount can be affixed to human suffering or the loss of human life, economic data can help to identify and quantify the current and projected future financial costs associated with ESRD. The 2000 report of the USRDS indicates that the total Medicare ESRD program cost will more than double, surpassing \$28 billion, by 2010, as the prevalence of kidney failure is projected to double. Currently, the total Medicare cost for ESRD is nearly \$20.1 billion. The annual average cost per ESRD patient is approximately \$58,000. These escalating costs serve to magnify the need to investigate new, and better apply, recently proven strategies for preventing progressive kidney disease.

In short, we can treat and maintain patients who have lost their kidney function but the critical need is to prevent the loss of kidney function and its complications in the first place. Meeting this vital goal can only be accomplished through more concerted research and education.

#### MAJOR CAUSES OF END STAGE RENAL DISEASE

Diabetes, a disease that affects 18 million Americans, is the most common cause of ESRD in the United States, accounting for 44 percent of new cases in 2002. The time from the onset of diabetes-related kidney disease to kidney failure is 5–7 years. With current projections that the epidemic of obesity-related diabetes mellitus will continue to soar, a dramatic increase in kidney disease is anticipated in the next 10 years.

Hypertension, or high blood pressure, is the next leading cause of ESRD, accounting for 27 percent of ESRD patients. Higher rates of hypertension can be found among certain age and ethnic groups. For example, 35 percent of African Americans have hypertension. Among new patients whose kidney failure was caused by high blood pressure, more than half (51.2 percent) were African American. It is also a disease of the aged and accounts for 37 percent of new ESRD cases in those 65 years old and above.

Despite recent progress and discoveries regarding the major causes of ESRD, it is among many areas of disease research that remain under-investigated. Researchers agree that significant inroads in previously understudied sub-fields need to be made. Significant among them, more focus and direction need to be introduced into the general field of renal research and patient and physician education.

#### LACK OF PUBLIC AWARENESS

A major problem with kidney disease is that it is largely a “Silent Disease”. In fact, of the 15 million Americans who have lost at least half of their kidney function, the vast majority have no knowledge of their condition. While people with chronic kidney disease may not show any symptoms, this does not mean that they are not going to have long-term damage to their kidney function, requiring dialysis or a transplant. These people may also be especially vulnerable to cardiovascular disease. If these 15 million people were identified early, there are new therapies, particularly special blood pressure drugs known as ACE inhibitors, which could be prescribed with potentially significant benefits. In addition, vigorous treatment of hypertension and other complications that cause illnesses and loss of productivity could be administered to the patients.

Given the cost to human life and to the Federal Government caused by the growing public health issues of CKD and ESRD, we urge this subcommittee to provide funding increases for kidney disease research.

## KIDNEY DISEASE RESEARCH

*National Institutes of Health (NIH)*

The ASN applauds Congress and members of the subcommittee for leading the bipartisan effort to double our investment in promising biomedical research supported and conducted by the NIH. NIH has served as a vital component in improving the Nation's health through research, both on and off the NIH campus, and in the training of research investigators, including nephrology researchers. Strides in biomedical discovery have had an impact on the quality of life for people with kidney disease. If we are to sustain this momentum and translate the promise of biomedical research into the reality of better health, this Nation must maintain its commitment to medical research. Unfortunately, since the doubling ended in 2003, funding for NIH has failed to keep pace with biomedical inflation and as a result, the NIH has lost more than 13 percent of its purchasing power. We support the recommendation of the Ad-Hoc Group for Medical Research Funding to add 6.7 percent to the NIH budget for a total of \$30.869 in fiscal year 2008.

*National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK)*

Many recent advances have been made in our understanding into the causes and progression of renal failure, such as: how diabetes and hypertension affect the kidney and the mechanisms responsible for acute renal failure. Despite these advances, the number of people with renal failure and the numbers who die of renal failure continue to increase each year. Most alarming is the significant increase in diabetes, the most common cause of chronic kidney failure, and its relationship to kidney disease. The ASN believes the rising incidence and prevalence of diabetes-related kidney disease warrants additional recourses to improve our understanding of the relationship between kidney disease and diabetes.

The NIDDK sponsors a number of activities that researchers hope will lead to improved detection, treatment and prevention of kidney disease and chronic kidney failure. To ensure ongoing kidney disease and kidney disease related research and important clinical trials infrastructure development we recommend a 6.7 percent increase for the NIDDK over fiscal year 2007 levels.

## ASN RESEARCH GOALS &amp; RECOMMENDATIONS FOR KIDNEY DISEASE

The ASN continues to evaluate its priorities for future kidney disease research. In the fall of 2004, the ASN conducted a series of research retreats to develop priorities to combat the growing prevalence of kidney disease in the United States. The ASN joined experts, both within and outside the renal community, and identified five areas requiring attention: acute renal failure, diabetic nephropathy, hypertension, transplantation, and kidney-associated cardiovascular disease.

The final research retreat report(s) highlighted priorities and contained three overriding recommendations. Theses include:

*Development of Core Centers for kidney disease research*

Expansion of the kidney research infrastructure in the United States can be achieved by vigorous funding of a program of kidney research core centers. Specifically, we propose that the number of kidney centers be increased with the goal of providing core facilities to support collaborative research on a local, regional and national level. It should be emphasized that such a program of competitively reviewed kidney core centers would facilitate investigator-initiated research in both laboratory and patient-oriented investigation. This approach is highly compatible with the collaborative research enterprise conceived in the NIH Road Map Initiative.

*Support programs/research initiatives that impact the understanding of the relationship between renal and cardiovascular disease*

It is now well recognized that chronic kidney dysfunction is an important risk factor for the development of cardiovascular disease. It is recommended that the NIDDK and NHLBI work cooperatively to support both basic and clinical science projects that will shed light on the pathogenesis of this relationship and to support the exploration of interventions that can decrease cardiovascular events in patients with CM). Thus, we specifically propose that NHLBI should support investigator-initiated research grants in areas of kidney research with a direct relationship to cardiovascular disease. Similarly, NHLBI should work collaboratively with NIDDK to support the proposed program of kidney core research centers.

*Continued support and expansion of investigator initiated research projects*

In each of the five subjects there are areas of fundamental investigation that require the support of investigator initiated projects, if ultimately progress is to be made in the understanding of the basic mechanisms that underlie the diseases proc-

esses. It is recommended that there should be an expansion of support for research in the areas that lend themselves to this mechanism of funding, by encouraging applications with appropriate program announcements and requests for proposals. In addition to vigorous support for RO1 grants, continued funding of Concept Development and R2 1/R33 grants is essential to support development of investigator-initiated clinical studies in these areas of high priority. Such funding is critical to accelerate the transfer of new knowledge from the bench to the bedside.

*Agency for Health Care Research and Quality (AHRQ)*

Complementing the medical research conducted at NIH, the AHRQ sponsors health services research designed to improve the quality of health care, decrease health care costs, and provide access to essential health care services by translating research into measurable improvements in the health care system. The AHRQ supports emerging critical issues in health care delivery and addresses the particular needs of priority populations, such as people with chronic diseases. The ASN firmly believes in the value of AHRQ's research and quality agenda, which continues to provide health care providers, policymakers, and patients with critical information needed to improve health care and treatment of chronic conditions such as kidney disease. The ASN supports the Friends of AHRQ recommendation of \$350 million for AHRO in fiscal year 2008.

CONCLUSION

Currently, there is no cure for kidney disease. The progression of chronic renal failure can be slowed, but never reversed. Meanwhile, millions of Americans face a gradual decline in their quality of life because of kidney disease. In many cases, abnormalities associated with early stage chronic renal failure remain undetected and are not diagnosed until the late stages. In sum, chronic renal failure requires our serious and immediate attention.

As practicing nephrologists, ASN members know firsthand the devastating effects of renal disease. ASN respectfully requests the subcommittees' continued support to enable the nephrology community to continue with its efforts to find better ways to treat and prevent kidney disease.

Thank you for your continued support for medical research and kidney disease research. To obtain further information about ASN, please go to <http://www.asn-online.org> or contact Paul Smedberg, ASN Director of Policy & Public Affairs at 202-416-0646.

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR PHARMACOLOGY AND  
EXPERIMENTAL THERAPEUTICS

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health fiscal year 2008 budget. ASPET is a 4,500 member scientific society whose members conduct basic and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases as well as increasing our knowledge regarding how these therapeutics work.

ASPET members are grateful for the U.S. Congress' historic support of the NIH. However, appropriations in recent years have failed to adequately fund the NIH to meet the scientific opportunities and challenges to our public health. For the fourth year in a row, the NIH research portfolio will not keep pace with the Biomedical Research and Development Price Index. After a 5 year bipartisan plan to double the NIH budget that ended in 2003, the budget is now going backwards. The administration's recommended fiscal year 2008 budget, if enacted would mean that the NIH's ability to conduct biomedical research would be cut by more than 13 percent in inflation adjusted dollars since fiscal year 2003.

To prevent this erosion and sustain the biomedical research enterprise, ASPET recommends that the NIH receive \$30.8 billion in fiscal year 2008. This would represent an increase of 6.7 percent (\$1.9 billion) over the fiscal year 2007 Joint Funding Resolution passed by Congress. ASPET joins other biomedical research organizations and professional societies, including the Ad Hoc Group for Medical Research, the Federation of American Societies for Experimental biology (FASEB), and Research!America, in advocating for a 6.7 percent increase in each of the next 3 years to help regain the momentum of discovery and pre-eminent research, and to help increase NIH's purchasing power and recover the losses caused by biomedical research inflation.

# NIH IMPROVES HUMAN HEALTH AND IS AN ECONOMIC ENGINE

Recent budget levels for the NIH constitute a retraction in the budget, sending the wrong signal to the best and brightest of American students who will not be able to or have chosen not to pursue a career in biomedical research. A diminished NIH research enterprise will mean a continued reduction in research grants and the resulting phasing-out of research programs and declining morale, an increasing loss of scientific opportunities such as the discovery of new therapeutic targets to develop, fewer discoveries that produce spin-off companies that employ individuals in districts around the country. In contrast, the requested funding level would provide the institutes with an opportunity to raise or at least maintain their paylines, fund more high quality and innovative research, and provide an incentive for young scientists to continue their research careers.

Many important drugs have been developed as a direct result of the basic knowledge gained from federally funded research, such as new therapies for breast cancer, the prevention of kidney transplant rejection, improved treatments for glaucoma, new drugs for depression, and the cholesterol lowering drugs known as statins that prevent 125,000 deaths from heart attack each year. AIDS related deaths have fallen by 73 percent since 1995 and the 5-year survival rate for childhood cancers rose to almost 80 percent in 2000 from under 60 percent in the 1970s. And for the first time in 70 years, the number of deaths from cancer has fallen. The link between basic research, drug discovery and clinical applications was vividly illustrated when three pharmacologists were awarded the 1998 Nobel Prize in Physiology or Medicine for their research on nitric oxide. More recently, NIH funded research for the 2005 Nobel Prize winners in chemistry. These scientists developed metal-containing molecules that are now being used by the pharmaceutical industry to aid in the drug discovery process. Historically, our past investment in basic biological research has led to innovative medicines that have virtually eliminated diphtheria, whooping cough, measles and polio in the United States 8 out of 10 children now survive leukemia. Death rates from heart disease and stroke have been reduced by half in the past 30 years. Molecularly targeted drugs such as Gleevec™ to treat adult leukemia do not harm normal tissue and dramatically improve survival rates. NIH research has developed a class of drugs that slow the progression of symptoms of Alzheimer's disease. The robust past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenetics and a reduction in adverse drug reactions that currently represent a major, worldwide health concern. But unless more robust funding is restored, such scientific opportunities from the human genome investment and others will be delayed, lost, or forfeited to biomedical research opportunities in other countries.

The human cost of not adequately investing in the NIH impact us all. The total economic cost to our Nation is also staggering: cancer, \$190 billion; obesity, \$99 billion; heart disease, \$255 billion; diabetes, \$131 billion; and arthritis, \$125 billion.

Scientific inquiry leads to better medicine but there remain challenges and opportunities that need to be addressed, including:

- The need to increase support for training and research in integrative/whole organ science to see how drugs act not just at the molecular level—but also in whole animals, including human beings.
- The need to meet public health concerns over growing consumer use of botanical therapies and dietary supplements. These products have unsubstantiated scientific efficacy and may adversely impact the treatment of chronic diseases, create dangerous interactions with prescription drugs, and may cause serious side effects including death among some users.

# SUPPORT FOR INTEGRATIVE ORGAN SYSTEM SCIENCE

ASPET supports efforts to increase funding for training and research in integrative organ system science (IOSS). IOSS is the study of responses in organs and organisms, including intact animals. Identification of isolated cellular and molecular components of drugs *in vitro* are important for identifying mechanisms of actions but are inadequate in determining all the complex interactions that happen *in vivo* in the actual organs of species. Because of the great advances in cellular and molecular biology over the past two decades, there has been much less emphasis in whole organ biology such that academic infrastructure in this area has eroded and there remain few faculty and institutions that can provide the appropriate scientific training in this important area of research. Too few individuals have opportunities to be trained beyond cellular and molecular techniques. As a consequence, the pool of talent with expertise in whole organs has greatly diminished and the biotechnology and pharmaceutical industry are having great difficulty finding well-trained whole organ scientists to fill critical positions in their drug discovery departments. As a

result of this training and research deficit, a more thorough and comprehensive examination of new therapeutic approaches may be compromised before clinical trials begin.

The lack of training and research opportunities to develop scientists well rounded in cellular, molecular and in vivo whole organ biology impacts progress in medicine and the training of future physicians. Development of preventive approaches and effective therapeutic strategies for many disorders with devastating health consequences and increasing incidence in an aging population will require intensive study at all levels from molecular to whole organ. For instance, obesity is not just a metabolic disorder. Obesity impacts many organ functions, including the heart, circulatory system, and brain. Similarly, clinical depression should not be viewed as just a neurological disorder because depression affects multiple organs in a variety of ways. And the discovery of new drugs to treat neurodegenerative diseases such as Alzheimer's and Parkinson's will ultimately need to look at complex whole animal systems. For these reasons, scientists must be trained to look broadly at complex medical problems afflicting humans. Medical progress in the post-genomic era needs scientists or teams of scientists who can integrate the results of studies in gene function at the molecular, cellular, organ system, whole animal and behavioral levels to fully understand the actions of current drugs and to facilitate the development of safe new drugs and treatment strategies.

To reverse the decline and adequately support training and research in integrative organ systems, integrative biology, program project grants, and pre and post-doctoral training programs should be implemented that support integrative training and research activities. Multi-disciplinary institutional and individual training and research grants on whole systems and integrative biology should be funded to investigate disease processes. ASPET is pleased that the National Institute of General Medical Sciences has recognized this training and research deficit and has funded four summer workshops to train students in integrative whole organ sciences. ASPET encourages other institutes to explore available mechanisms to begin developing a pool of talented scientists with the appropriate skills in integrative, whole organ systems biology. While many industrial concerns provide limited support for training and research at the post-doctoral level, their efforts remain necessarily focused on drug discovery and development. It is the role of the NIH and academic institutions to provide adequate training opportunities to develop the next generation of integrative scientists.

Support for training and research in integrative whole organ sciences has been affirmed in the fiscal year 2002 U.S. Senate Labor/Health and Human Services & Related Agencies Appropriations Report (107-84). The Senate report supports ASPET recommendation that "Increased support for research and training in whole systems pharmacology, physiology, toxicology, and other integrative biological systems that help to define the effects of therapy on disease and the overall function of the human body." These principles and recommendations are also affirmed in the FASEB Annual Consensus Conference Report on Federal Funding for Biomedical and Related Life Sciences Research for Fiscal Year 2002.

#### SUPPORT FOR RESEARCH ON BOTANICALS AND HERBAL THERAPIES TO MEET PUBLIC HEALTH NEEDS

ASPET has for years supported peer-reviewed pharmacological examination of the mechanisms of actions of medicinal plants and is pleased that the NIH's National Center for Complementary and Alternative Medicine (NCCAM) continues rigorous investigations into the basic biology of various botanical agents. ASPET continues to recommend increased support to study the interaction of botanical remedies and dietary supplements with prescription medications. This support is critical to the promotion and funding of the highest quality research in botanical medicine, will help meet urgent needs of this neglected area of biological research, and will address a growing public health problem. Support for highly innovative research on botanicals should be encouraged among all institutes and centers.

The increased use of botanical and dietary supplements by consumers to treat various ailments and diseases is a major public health concern. One national survey reported that in 1997 an estimated 15 million adults (18.4 percent of all prescription users) took herbal remedies concurrently with prescription medicines. Between 1990 and 1997, the use of herbal products grew by 380 percent. Although there is little solid scientific evidence to support the therapeutic efficacy of many botanical and dietary supplement products, the industry records over \$19 billion in annual sales. Botanical products were once regulated as drugs and the FDA had authority to prevent the sale of unproven herbal ingredients. However, legislative reforms in 1994 eliminated the FDA's authority to test or approve herbal products prior to mar-

keting. Thus, at a time when many more consumers are using more herbal products, there is little research on either their clinical efficacy or basic mechanisms of action. The growing use of herbal products by consumers, their interactions with prescription drugs—and mechanisms of such interactions—represent a serious and growing public health problem that demands scientific attention and redress by regulatory and legislative action.

Through the NIH, research into the safety and efficacy of botanical products can be conducted in a rigorous and high quality manner. Sound pharmacological studies will help determine the value of botanical preparations and the potential for their interactions with prescription drugs as well as chronic disease processes. This research will allow the FDA to review the available pharmacology and review valid evidence-based reviews to form a valid scientific foundation for regulating these products.

#### CONCLUSION

The biomedical research enterprise is facing a critical moment as funding stagnates. Reversing this trend and helping to sustain the extraordinary scientific progress that has been made at the NIH and at the academic institutions funded by the NIH over the past years is a major challenge facing this subcommittee. A 6.7 percent increase for the NIH in fiscal year 2008 will allow the NIH to make greater strides to prevent, diagnose and treat disease, improving the health of our Nation. A 6.7 percent increase in the fiscal year 2008 NIH budget will begin to restore NIH's role as a national treasure that attracts and retains the best and brightest scientists to biomedical research.

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#### PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

##### OVERVIEW

The American Society of Tropical Medicine and Hygiene appreciates the opportunity to submit written testimony to the House Labor, Health and Human, Services, and Education Appropriations Subcommittee. With more than 3,300 members, ASTMH is the world's largest professional membership organization dedicated to the prevention and control of tropical diseases. We represent, educate, and support tropical medicine scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals from this field.

We respectfully request that the subcommittee provide the following allocations in the fiscal year 2008 Labor, Health and Human, Services, and Education Appropriations bill to support a comprehensive effort to eradicate malaria:

- \$18 million to the Centers for Disease and Control and Prevention (CDC) for malaria research, control, and program evaluation efforts with a \$6 million set-aside for program monitoring and evaluation;
- \$30.8 billion to National Institutes of Health (NIH);
- \$4.7 billion to the National Institute of Allergy and Infectious Diseases (NIAID);
- and
- \$70.8 million to the Fogarty International Center (FIC).

We very much appreciate the subcommittee's consideration our views, and we stand ready to work with the subcommittee members and staff on these and other important global health matters.

##### ASTMH

ASTMH plays an integral and unique role in the advancement of the field of tropical medicine. Its mission is to promote world health by preventing and controlling tropical diseases through research and education. As such, the Society is the principal membership organization representing, educating, and supporting tropical medicine scientists, physicians, researchers, and other health professionals dedicated to the prevention and control of tropical diseases. Our members reside in 46 States and the District of Columbia and work in a myriad of public, private, and non-profit environments, including academia, the U.S. military, public institutions, Federal agencies, private practice, and industry.

ASTMH aims to advance policies and programs that prevent and control those tropical diseases which particularly impact the global poor.

## TROPICAL MEDICINE AND TROPICAL DISEASES

The term “tropical medicine” refers to the wide-ranging clinical work, research, and educational efforts of clinicians, scientists, and public health officials with a focus on the diagnosis, mitigation, prevention, and treatment of diseases prevalent in the areas of the world with a tropical climate. Most tropical diseases are located in either sub-Saharan Africa, parts of Asia (including the Indian subcontinent), or Central and South America. Many of the world’s developing nations are located in these areas; thus tropical medicine tends to focus on diseases that impact the world’s most impoverished individuals.

The field of tropical medicine encompasses clinical work treating tropical diseases, work in public health and public policy to prevent and control tropical diseases, basic and applied research related to tropical diseases, and education of health professionals and the public regarding tropical diseases.

Tropical diseases are illnesses that are caused by pathogens that are prevalent in areas of the world with a tropical climate. These diseases are caused by viruses, bacteria, and parasites which are spread through various mechanisms, including airborne routes, sexual contact, contaminated water and food, or an intermediary or “vector”—frequently an insect (e.g. a mosquito)—that transmits a disease between humans in the process of feeding.

## MALARIA

Malaria is a global emergency affecting mostly poor women and children; it is an acute and sometimes fatal disease caused by the single-celled *Plasmodium* parasite that is transmitted to humans by the female *Anopheles* mosquito.

Malaria is highly treatable and preventable. The tragedy is that despite this, malaria is one of the leading causes of death and disease worldwide. According to the CDC, as many as 2.7 million individuals die from malaria each year, with 75 percent of those deaths occurring in African children. In 2002, malaria was the fourth leading cause of death in children in developing countries, causing 10.7 percent of all such deaths. Malaria-related illness and mortality extract a significant human toll as well as cost Africa’s economy \$12 billion per year perpetuating a cycle of poverty and illness. Nearly 40 percent of the world’s population lives in an area that is at high risk for the transmission of malaria.

Fortunately, malaria can be both prevented and treated using four types of relatively low-cost interventions: (1) the indoor residual spraying of insecticide on the walls of homes; (2) long-lasting insecticide-treated nets; (3) Artemisinin-based combination therapies; and (4) intermittent preventive therapy for pregnant women. However, limited resources preclude the provision of these interventions and treatments to all individuals and communities in need.

## REQUESTED MALARIA-RELATED ACTIVITIES AND FUNDING LEVELS

*CDC Malaria Efforts*

ASTMH calls upon Congress to fund a comprehensive approach to malaria control, including public health infrastructure improvements, increased availability of existing anti-malarial drugs, development of new anti-malarial drugs and better diagnostics, and research to identify an effective malaria vaccine. Much of this important work currently is underway; however, additional funds and a sustaining commitment from the Federal Government are necessary to make progress in malaria prevention, treatment, and control.

The CDC conducts research to address pertinent questions regarding issues related to malaria as well as engages in prevention and control efforts, especially as a lead collaborator on the President’s Malaria Initiative. To maximize CDC’s efforts and expertise, we request \$18 million for the CDC for malaria research, control, and program evaluation efforts with a \$6 million set-aside for program monitoring and evaluation. The CDC maintains several domestic activities, international activities, and research activities, including:

- Surveillance of malaria
- Investigations of locally transmitted malaria
- Advice and consultations such as a toll-free information service
- Diagnostic assistance to State health departments on malaria diagnosis
- Research to improve understanding of malaria
- International Activities including the President’s Malaria Initiative (PMI), the Amazon Malaria Initiative (AMI), the West Africa Network against Malaria during Pregnancy

CDC collaborations support treatment and prevention policy change based on scientific findings; formulation of international recommendations through membership

on World Health Organization (WHO) technical committees; and work with Ministries of Health and other local partners in malaria-endemic countries and regions to develop, implement, and evaluate malaria programs. In addition, CDC has provided direct staff support to WHO; UNICEF; the Global Fund to Fight AIDS, Tuberculosis, and Malaria; and the World Bank—all stakeholders in the Roll Back Malaria (RBM) Partnership.

#### *NIH Malaria Efforts*

As the Nation's and world's premier biomedical research agency, the NIH and its Institutes and Centers play an essential role in the development of new anti-malarial drugs, better diagnostics, and an effective malaria vaccine. NIH estimates that its fiscal year 2007 spending on malaria research will total \$101 million while malaria vaccine efforts will receive \$45 million. ASTMH urges that NIH malaria research portfolio and budget be increased by at least 6.7 percent in fiscal year 2008. To support a comprehensive effort to eradicate malaria, ASTMH respectfully requests the following funding:

- \$30.8 billion to NIH;
- \$4.7 billion NIAID; and
- \$70.8 million to the Fogarty International Center to support training in biomedical research on behalf of the developing nations of the world.

#### *National Institute of Allergy and Infectious Diseases (NIAID)*

NIH estimates that in fiscal year 2007 it will spend approximately \$101 million for malaria research and \$45 million for research related specifically to creating a malaria vaccine. NIAID, the lead institute for this research, has developed an Implementation Plan for Global Research on Malaria, which is focused on five research areas: vaccine development, drug development, diagnostics, vector control, and infrastructure and research capability strengthening.

- Vaccine Development.*—No malaria vaccine currently exists. NIAID introduced a research agenda for malaria vaccine development in 1997, the aim of which is to support discovery and characterization of new vaccine candidates, production of pilot lots, and clinical evaluation of promising candidate vaccines.
- Drug Development.*—Drug-resistant malaria increasingly is being reported around the world. NIAID is involved in improving the monitoring of drug resistance and developing new drugs.
- Diagnostics.*—Improved diagnostic tools are essential in making early diagnosis and providing rapid treatment.
- Vector Control.*—NIAID is working to create next-generation, environmentally-friendly insecticides for public health use.
- Strengthening Infrastructure and Research Capability.*—NIAID is working with partners to strengthen research capabilities of scientists in their own countries.

ASTMH encourages the subcommittee to increase funding for NIAID to ensure that we do not lose ground in the fight against malaria.

#### *Fogarty International Center (FIC)*

The FIC addresses global health challenges and supports the NIH mission through myriad activities, including: collaborative research and capacity building projects relevant to low- and middle-income nations; institutional training grants designed to enhance research capacity in the developing world; the Forum for International Health, through which NIH staff share ideas and information on relevant programs and develop input from an international perspective on cross-cutting NIH initiatives; the Multilateral Initiative on Malaria, which fosters international collaboration and co-operation in scientific research against malaria; and the Disease Control Priorities Project, which is a partnership to develop recommendations on effective health care interventions for resource-poor settings. ASTMH urges the subcommittee to allocate additional resources to the FIC in fiscal year 2008 to increase these efforts, particularly as they apply to abatement and treatment of malaria.

#### CONCLUSION

Thank you for your attention to these important global health matters. We know that you face many challenges in choosing funding priorities and we hope that you will provide the requested fiscal year 2008 resources to those agencies programs identified above. ASTMH appreciates the opportunity to share its views, and we thank you for your consideration of our requests.

## PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

## SUMMARY.—FUNDING RECOMMENDATIONS

[In millions of dollars]

	Amount
National Institutes of Health .....	30,537
National Heart, Lung and Blood Institute .....	3,114
National Institute of Allergy and Infectious Disease .....	4,675
National Institute of Environmental Health Sciences .....	683
Fogarty International Center .....	70
National Institute of Nursing Research .....	146
Centers for Disease Control and Prevention .....	10,700
National Institute for Occupational Safety and Health .....	253
Environmental Health: Asthma Activities .....	70
Tuberculosis Control Programs .....	252.4

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society that focuses on respiratory and critical care medicine. For 100 years, the ATS has continued to play a leadership role in scientific and clinical expertise in diagnosis, treatment, cure and prevention of respiratory diseases. With approximately 18,000 members who help prevent and fight respiratory disease around the globe, through research, education, patient care and advocacy, the Society's long-range goal is to decrease morbidity and mortality from respiratory disorders and life-threatening acute illnesses.

## LUNG DISEASE IN AMERICA

Lung disease is a serious health problem in the United States. Each year, close to 400,000 Americans die of lung disease. Lung disease is responsible for one in every seven deaths, making it America's number three cause of death. More than 35 million Americans suffer from a chronic lung disease. In 2005, lung diseases cost the U.S. economy an estimated \$157.8 billion in direct and indirect costs.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include chronic obstructive pulmonary disease, lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma and severe acute respiratory syndrome (SARS).

The ATS is pleased that the subcommittee provided increases in the National Institutes of Health (NIH) budget last fiscal year. However, we are extremely concerned that the President's fiscal year 2008 budget proposes a 1.7 percent cut for NIH and significant cuts for the Centers for Disease Control and Prevention (CDC). We ask that this subcommittee recommend a 6.7 percent increase for NIH so that the NIH can respond to biomedical research opportunities and public health needs. In order to stem the devastating effects of lung disease, research funding must continue to grow to sustain the medical breakthroughs made in recent years. We also ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including strengthened TB control to prevent the spread of extensively drug-resistant (XDR)-TB, and occupational safety and health research and training. There are three lung diseases that illustrate the need for further investment in research and public health programs: Chronic Obstructive Pulmonary Disease, pediatric lung disease, asthma and tuberculosis.

## COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide. Yet, COPD remains relatively unknown to most Americans. COPD is the term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis and is a growing health problem.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It is estimated that 11.2 million patients have COPD while an additional 12 million Americans are unaware that they have this life threatening disease.

According to the National Heart, Lung and Blood Institute (NHLBI), COPD cost the U.S. economy an estimated \$37 billion per year. We recommend the subcommittee encourage NHLBI to devote additional resources to finding improved treatments and a cure for COPD.

Medical treatments exist to relieve symptoms and slow the progression of the disease. Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Despite these leads, the ATS feels that research resources committed to COPD are not commensurate with the impact the disease has on the United States and that more needs to be done to make Americans aware of COPD, its causes and symptoms. The ATS commends the NHLBI for its leadership on educating the public about COPD through the National COPD Education and Prevention Program. As this initiative continues, we encourage the NHLBI to maintain its partnership with the patient and physician community.

While additional resources are needed at NIH to conduct COPD research, CDC has a role to play as well. The ATS encourages the CDC to add COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the National Health Information Survey (NHIS) and the Behavioral Risk Factor Surveillance Survey (BRFSS). By collecting information on the prevalence of COPD, researchers and public health professionals will be better able to understand and control the disease.

#### PEDIATRIC LUNG DISEASE

Lung disease affects people of all ages. The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. However, of the seven leading causes of infant mortality, four are lung diseases or have a lung disease component. In 2003, lung diseases accounted for 18 percent of all deaths under 1 year of age. It is also widely believed that many of the precursors of adult respiratory disease start in childhood. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

The pediatric origins of chronic lung disease extend back to early childhood factors. For example, many children with respiratory illness are growing into adults with COPD. In addition, it is estimated that close to 20.5 million people suffer from asthma, including an estimated 6.2 million children. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. Asthma is the third leading cause of hospitalization among children under the age of 15 and is the leading cause of chronic illness among children.

#### ASTHMA

The ATS believes that the NIH and the CDC must play a leadership role in assisting individuals with asthma. National statistical estimates show that asthma is a growing problem in the United States. Approximately 22.2 million Americans currently have asthma, of which 12.2 million had an asthma attack in 2005. African Americans have the highest asthma prevalence of any racial/ethnic group. The age-adjusted death rate for asthma in the African-American population is three times the rate in whites.

#### ASTHMA SURVEILLANCE

There is a need for more data on regional and local asthma prevalence. In order to develop a targeted public health strategy to respond intelligently to asthma, we need locality-specific data. CDC should take the lead in collecting and analyzing this data and Congress should provide increased funding to build these tracking systems.

In fiscal year 2007, Congress provided approximately \$31.9 million for CDC's National Asthma Control Program. The goals of this program are to reduce the number of deaths, hospitalizations, emergency department visits, school or work days missed, and limitations on activity due to asthma. We recommend that CDC be provided with \$70 million in fiscal year 2008 to expand the program and establish grants to community organizations for screening, treatment, education and prevention of childhood asthma.

#### SLEEP

Sleep is an essential element of life, but we are only now beginning to understand its impact on human health. Several research studies demonstrate that sleep illnesses and sleep disordered breathing affect over 50 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being deter-

mined, but is known to include traffic accidents, lost work and school productivity, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. We cannot appropriately address these problems if we do not consider how chronic sleep loss contributes to them. Despite the increased need for study in this area, research on sleep and sleep-related disorders has been underfunded. The ATS recommends increased funding to support activities related to sleep and sleep disorders at the CDC, including for the National Sleep Awareness Roundtable (NSART), and research on sleep disorders at the Nation Center for Sleep Disordered Research (NCSDR) at the NHLBI.

#### TUBERCULOSIS

Tuberculosis (TB) is a global public health crisis that remains a concern for the United States. Tuberculosis is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis*. Tuberculosis primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine. The statistics for TB are alarming. Globally, one-third of the world's population is infected with the TB germ, 8.8 million active cases develop each year and 1.6 million people die of tuberculosis annually. It is estimated that 9–14 million Americans have latent tuberculosis. Tuberculosis is the leading cause of death for people with HIV/AIDS.

According to the CDC, although the overall rate of new TB cases is declining in the United States, the annual rate of decrease in TB cases has slowed significantly, from about 7.3 percent (1993 to 2000) to 3.8 percent currently (2000–2006). This rate represents one of the smallest declines since 1992, when over \$1 billion was spent in New York City alone to regain control of TB. The ATS is concerned that TB rates in African Americans remain high and that TB rates in foreign-born Americans are growing.

The emergence of extensively drug-resistant XDR-TB has created a global health emergency. Because it is resistant to most of the drugs used to treat TB, XDR-TB is virtually untreatable and has an extremely high fatality rate. In one of the latest outbreaks in South Africa from late 2005 until early 2006, XDR-TB killed 52 out of 53 infected patients. According to data released by the CDC in March, between 1993 and 2006, there were 49 reported XDR-TB cases in the United States. Because of the ease with which TB can spread, XDR TB will continue to pose a serious risk to the United States as long as it exists anywhere else in the world.

While we urge immediate action in response to the XDR-TB emergency, we also recognize the best way to prevent the future development of other resistant strains of tuberculosis is through supporting effective tuberculosis control programs in the United States and throughout the globe. We ask the subcommittee to take the first steps to eliminating TB in the United States and prevent further outbreaks of drug resistant forms of TB. The ATS, in collaboration with the National Coalition for Elimination of Tuberculosis, recommends an increase of \$120 million in fiscal year 2008 for CDC's National Program for the Elimination of Tuberculosis.

The NIH also has a prominent role to play in the elimination of tuberculosis. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances have put the goal of an effective TB vaccine within reach. The National Institute of Allergy and Infectious Disease has developed a Blueprint for Tuberculosis Vaccine Development. We encourage the subcommittee to fully fund the TB vaccine blueprint. We also encourage the NIH to continue efforts to develop drugs to combat multi-drug resistant tuberculosis a serious emerging public health threat.

#### *Fogarty International Center TB Training Programs*

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area of TB treatment and research. These training grants should be expanded and offered to all institutions. The ATS recommends Congress provide \$70 million for FIC to expand the TB training grant program from a supplemental grant to an open competition grant.

#### RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The National Institute of Occupational Safety and Health (NIOSH) is the sole Federal agency responsible for conducting research and making recommendations for the prevention of work-related diseases and injury. In addition to conducting research, NIOSH investigates potentially hazardous working conditions, makes recommendations and disseminates information on preventing workplace disease, in-

jury, and disability; and provides training to occupational safety and health professionals. The ATS recommends that Congress provide \$253 million for NIOSH to expand or establish the following activities: the National Occupational Research Agenda (NORA); tracking systems for identifying and responding to hazardous exposures and risks in the workplace; emergency preparedness and response activities; and training medical professionals in the diagnosis and treatment of occupational illness and injury.

#### CONCLUSION

Lung disease is a growing problem in the United States. It is this country's third leading cause of death. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of 1 year. Worldwide, tuberculosis is one of the leading infectious disease killers. The level of support this subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers. The ATS appreciates the opportunity to submit this statement to the subcommittee.

#### PREPARED STATEMENT OF AMERICANS FOR THE ARTS

Americans for the Arts and the Los Angeles County Arts Commission respectfully request the subcommittee to adopt an appropriation of \$53 million for the Arts in Education programs of the U.S. Department of Education. We also ask that it require the U.S. Department of Education to conduct much-needed research on the status of arts education, including the Fast Response Statistical Survey (FRSS) and the National Assessment of Educational Progress (NAEP).

Before considering funding levels, members of the subcommittee need to be aware of a simple but breathtaking fact: Students with an education rich in the arts have better grade point averages in core academic subjects, score better on standardized tests, and have lower drop-out rates than students without arts education. This fact is demonstrated by an increasing amount of compelling research. It is not seriously contested. Further, research confirms that these results occur across the socio-economic range.

Artists believe that the arts are important for their own sake. Educators know they are rigorous and standards-based, and they are essential for supporting the learning styles of all students while providing them with the unique opportunity to develop problem solving skills, to develop critical thinking skills and to foster their creativity. In essence, the arts help students develop skills that are needed for the 21st century workforce. In fact, CEOs have stated that the MFA (Masters in Fine Arts) is the new MBA and seek employees that have had a solid arts education. You can agree or disagree with us, of course. But you can't ignore the research, which shows that the arts help kids do better in school. And for that reason, we believe that the Federal Government has an essential role in ensuring that all children have access to excellent arts education.

For several decades, the U.S. Department of Education's Arts in Education programs have provided funding for the national programs of the John F. Kennedy Center for the Performing Arts and VSA arts (formerly Very Special Arts). Since 2001 they have also run two important competitive grant programs:

- The Model Development and Dissemination program identifies, develops, documents, and disseminates models of excellence in arts education that impact schools and communities nationwide. These projects strengthen student learning through standards-based arts education and integration of arts instruction into other subject areas.
- The Professional Development grants program supports projects that serve as national models for effective professional development that improve instruction for arts specialists and classroom teachers. State and local education agencies can adapt these models to provide rigorous arts instruction for all students.

A recent Model Development grant was given to the Los Angeles Unified School District, in partnership with Inner-City Arts, a non-profit organization providing arts learning services to students in the district, and the University of California, Los Angeles (UCLA) Graduate School of Education and Information Sciences. The three-year Arts in the Middle (AIM) Project will expand and rigorously evaluate an innovative, cohesive model for delivery of arts-based instruction to remedial grade six English learners. The Project's strategy will extend community resources to under-resourced urban middle schools in order to improve academic performance among English learners by integrating standards-based arts education within the core Language Arts curricula of grade six students. The Project's target population is remedial grade six students who are at extreme high risk of academic failure due

to low levels of English Language Development. Assuming it is successful, the goal is to replicate it within other Los Angeles schools. This project directly supports the school district's 10-year plan for arts education.

With increased funding, the Arts in Education programs will be able to support additional such models that improve arts learning in high-poverty schools, and findings from the model projects may be more widely disseminated.

With regard to another aspect of our request: despite research showing the positive effects of arts education, there is a serious lack of empirical data on how much arts education is being delivered in our Nation's schools. We do not have comprehensive, reliable information about student access to arts instruction or student performance in the arts. The last Fast Response Survey report was for the 1999–2000 school year, and the next round is long overdue.

Congress has repeatedly urged the Department of Education to implement the Fast Response Survey in the arts to no avail. In public statements, U.S. Secretary of Education Margaret Spellings has said, "Art, dance, music, and theater are as much a part of education as reading, math, and science." And yet, the Department has told Congress that among the "many tough choices" made in the area of research, the arts survey did not rate as a priority.

The Senate included report language in the fiscal year 2007 appropriations bill that explicitly directed the Department of Education to conduct the FRSS, and it also provided funding for that purpose. As you know, however, the bill did not become law, and therefore the Department of Education has been able to delay implementing the FRSS for yet another year. We thank this subcommittee for taking this step last year and urge you to adopt similar language in your fiscal year 2008 bill.

Good data does exist in some localities, but only data that is national in scope will allow Congress to make national policy. We would like to tell you about data was gathered and used to affect policy in Los Angeles County. The task was an essential step in helping the County and community stakeholders such as school districts, arts organizations, elected officials, business leaders, foundations, and corporations strategically organize their efforts to restore K–12 arts education. We hope the story of how the information was collected, and the way it was used, will convince you of the need to compel the Department of Education to collect national data.

In 2000, the Arts Commission commissioned the Arts in Focus survey, which detailed the status of arts education for 1.7 million students in 82 school districts. These students represent 27 percent of all public school students in the State, and 3.4 percent of all public school students in the country. With 80 of the 82 superintendents in the County participating, it was found that:

- 54 percent of school leaders reported no adopted arts policy and 37 percent reported no defined sequential arts education in any discipline, at any school level.
- 64 percent reported no district level arts coordinator, and the current average ratio of credentialed arts teachers to students was 1:1,200.
- Nearly 50 percent reported "lack of instructional time in students' schedules" as their most significant challenge.
- Many districts would not have arts programs without the support of parents and partnerships with non-profit arts organizations. Seventy-eight percent of districts allocated less than 2 percent of their budget to arts education and 82.3 percent used partnerships with non-profit organizations to provide arts education.

One hundred percent of superintendents who were interviewed stated that they believe in the importance of the arts. However, what the data revealed was the lack of an infrastructure to support arts education and, given the three decades without sequential arts education, limited capacity of school districts to incorporate it back into the school day.

In response to the findings of Arts in Focus, Los Angeles County (the Arts Commission in partnership with the Los Angeles County Office of Education) embarked on a year-long, community-based planning process. In 2002, the County Board of Supervisors, the County Board of Education and the County Arts Commission unanimously adopted Arts for All: Los Angeles County Regional Blueprint for Arts Education, which presents a series of policy changes, educational initiatives, and establishment of a new infrastructure to ensure all 1.7 million students receive a high-quality K–12 arts education.

The first goal of the Blueprint is to help school districts create a sustainable infrastructure for arts education by conducting a needs assessment and utilizing district data to develop and adopt an arts education policy and long-range budgeted plan with benchmarks. To date, 20 school districts are at various stages of receiving technical assistance from a coach to strategically, and thoughtfully, identify and imple-

ment key budgeted priorities for arts education in the areas of standards-based curriculum, instruction and methodology, assessment, professional development, program administration and personnel, partnerships and collaborations, funding, resources and facilities, and evaluation.

As a key strategy in the Blueprint, the County created the Arts Education Performance Indicators report, or AEPI, to collect pertinent school district data to track the status of an arts education infrastructure based on five critical factors: an arts education policy adopted by the school board; an arts education plan adopted by the school board; a district level arts coordinator; an arts education budget of at least 5 percent of the district's total budget; and a student to credentialed arts teacher ratio of no higher than 400:1. With these pieces in place, school districts can deliver sustainable arts education.

The AEPI is released every other year. It is interesting to note that for the 2005 report, those districts making the greatest progress in achieving the five critical success factors received technical assistance while those showing little to no improvement did not. AEPI is an invaluable tool in providing a county-wide picture of the status of an arts education infrastructure, target technical assistance to help school districts plan, keep arts education visible and at the forefront of policy discussions, provide a mechanism for school districts to self-evaluate and reflect on their progress in providing equal access to a quality arts education and to compare themselves to other districts, and encourage County-wide dialogue on arts education among diverse stakeholders in the community—from elected officials, to educators, to parents and students.

Access to up-to-date, accurate data is imperative to drive strategic planning and policy change. In addition, Arts for All illustrates the importance of providing customized assistance to help school districts effectively plan for the implementation of arts education based on identified needs and priorities. Without this help, we have found that it is difficult for school districts to use available funds effectively—including, for example, Federal Title I funds.

You may be aware that the fiscal year 2006–2007 budget for the State of California includes \$500 million in one-time funding for arts education and physical education equipment, supplies and professional development and \$105 million in ongoing funding especially for arts education personnel, supplies, materials, and professional development. As it turns out, the districts that have received technical assistance and that have established policies and plans are able to effectively and strategically utilize this funding. Seventeen County school districts have expressed an interest in receiving arts education planning assistance through Arts for All in light of the new State money. With these additional school districts, 37 districts in Los Angeles County will be planning for and implementing standards-based arts education—close to 50 percent of County school districts—with more school districts joining Arts for All each year.

Each level of government has its part to play, in concert with stakeholders at each level. We have described the massive commitment of Los Angeles County government to providing excellent arts education, and we have touched on the increased recognition by the State of California of its responsibility to help. The Federal Government needs to step up as well. It has a unique role in collecting and publishing data, and an essential role in supporting, researching and disseminating locally developed projects. Both of these roles are the focus of this testimony.

We would also like to ask you to encourage local districts to use Federal education funds, such as Title I, to institute data collection and technical assistance programs similar to what was done in Los Angeles County. They should also use Federal funds to hire local district-wide arts education coordinators.

Finally, we would like to mention that the NAEP—the national arts “report card”—is scheduled to be administered in 2008, and must stay on track. It is designed to measure students’ knowledge and skills in dance, music, theatre, and visual arts, and it provides critical information about the arts skills and knowledge of our Nation’s students. The last arts NAEP was performed in 1997. Like the FRSS, the next round is long overdue.

Thank you very much for the opportunity to submit this testimony.

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PREPARED STATEMENT OF THE AMERICANS FOR NURSING SHORTAGE RELIEF (ANSR)  
ALLIANCE

The undersigned organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony regarding fiscal year 2008 appropriations for Title VIII—Nursing Workforce Development Programs. The ANSR Alliance is comprised of 52 national nursing organizations that united in 2001 to identify and pro-

mote creative strategies for addressing the nursing and nurse faculty shortages, including passage of the Nurse Reinvestment Act of 2002.

The ANSR Alliance stands ready to work with lawmakers to advance programs and policy that will sustain and strengthen our Nation's nursing workforce. To ensure that our Nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century, ANSR urges Congress to:

- Appropriate at least \$200 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA) in fiscal year 2008.
- Restore the Advanced Education Nursing program (Sec. 811) and fund it at a level on par with the proposed fiscal year 2008 increase for the other Title VIII programs.

#### NURSING SHORTAGE

Nurses play a critical role in our Nation's health care system. An estimated 2.9 million licensed registered and advanced practice registered nurses (RNs and APRNs) represent the largest professional occupation of all health care workers providing patient care in virtually all locations in which health care is delivered. The diversity of practice settings and differing scopes of practice makes the nursing shortage an even more complex challenge. Some facts to consider:

- The nursing workforce is aging. In 1980, 26 percent of RNs were under the age of 30. Today, approximately 8 percent of RNs are under the age of 30 with the average nurse being 46.8 years of age;
- Approximately half of the RN workforce is expected to reach retirement age within the next 10 to 15 years. The average age of new RN graduates is almost 30 years old;
- A December 2005 Bureau of Labor Statistics report projected that registered nursing would create the second largest number of new jobs among all occupations within 9 years. In addition, employment of RNs is expected to grow much faster than average for all occupations through 2014. It is anticipated that approximately 703,000 additional jobs, for a total of 3,096,000, will be available for RNs by that date;
- The national nursing shortage also is affecting our Nation's 7.6 million veterans who receive care through the 1,300 Department of Veterans Affairs (VA) health care facilities. The VA, the largest sole employer of RNs in the United States, has a 10 percent RN vacancy rate;
- The nurse faculty vacancies in the United States continued to grow even as the numbers of full- and part-time educators increased during the 2005–2006 academic year. According to the National League for Nursing's 2006 Nurse Faculty Census, the estimated number of budgeted, unfilled, full-time positions in 2006 was 1,390. This number represents a 7.9 percent vacancy rate in baccalaureate and higher degree programs, which is an increase of 32 percent since 2002; and a 5.6 percent vacancy rate in associate degree programs, which translates to a 10 percent rise in the same period.

#### NURSING SUPPLY IMPACTS AMERICA'S EMERGENCY PREPAREDNESS

The National Center for Health Workforce Analysis at the Bureau of Health Professions in HRSA reports that the nursing shortage makes it challenging for the health care sector to meet current service needs. Nursing shortfalls exacerbating capacity insufficiencies throughout the health care system have ripple effects, for example, seen in the problems encountered by most communities' day-to-day emergency care services. Facing a pandemic flu or other natural or man-made disaster of significant proportions makes the nursing shortage an even greater national concern, as well as an essential part of national preparedness and response planning.

Nurses play a critical role as front-line, first-responders. When word of the devastation caused by Hurricanes Katrina and Rita reached nurses across the country, they immediately volunteered in American Red Cross shelters, medical clinics, and hospitals throughout that widespread region. Nurses and advanced practice registered nurses (e.g., nurse midwives, nurse practitioners, clinical nurse specialists and certified registered nurse anesthetists) are particularly critical national resources in an emergency, able to provide clinical nursing care as well as primary care. During Katrina and Rita, nurse midwives delivered babies in airplane hangars, and nurses trained in geriatric care assisted in caring for those traumatized by their evacuation from the comforts of their homes, assisted living facilities or nursing homes. Nurse practitioners diligently staffed temporary and permanent health care clinics to provide needed primary care to hurricane victims. Many nurses con-

tributed not just through their clinical expertise, but also by offering psychological support as they listened to survivors recount their stories of pain and tragedy.

These stories seem particularly relevant in demonstrating the essential assistance nurses provide during tragedies, and reinforce the need to ensure an adequate supply of all types of nurses. Unless steps are taken now, the Nation's ability to respond to disasters will be further hindered by the growing nursing shortage. An investment in the nursing workforce is a reasonable and cost-effective investment toward rebuilding the public health infrastructure and increasing our Nation's health care readiness and emergency response capabilities.

#### DESPERATE NEED FOR NURSE FACULTY

After years of declining interest, the nursing profession is seeing a resurgence of interest in the profession. Many people in America have come to find nursing an attractive career because of job openings, salary levels, and the opportunity to help others. However, the common theme among prospective nursing students is that due to a lack of enrollment openings, owing to faculty shortages, they can face waiting periods of up to 3 years before matriculating. When all nursing programs are considered, the number of qualified applications turned away during the 2004–2005 academic year was estimated to be nearly 147,000 by the National League for Nursing. Without sufficient support for current nurse faculty and adequate incentives to encourage more nurses to become faculty, nursing schools will fail to have the teaching infrastructure necessary to educate and train the next generation of nurses that the Nation so desperately need.

The current and deepening nurse faculty shortfall is the critical reason that the Advanced Education Nursing line item in the Title VIII programs must be fully funded. This program supported 11,949 graduate nursing students in fiscal year 2005. The students that are supported by this funding are the pool of future faculty for the nursing profession. Whether supporting students in clinical education or as faculty in schools of nursing, it is essential that advanced education nursing funding be restored.

#### FUNDING REALITY

Enacted in 2002, the Nurse Reinvestment Act (Public Law 107–205) addressed new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our Nation's nursing workforce. For example:

- Fiscal Year 2005 Nursing Education Loan Repayment Program.*—Of the 4,465 applicants, 803 awards were made (599 initial 2-year awards and 204 amendment awards) with 18 percent of applicants receiving awards.
- Fiscal Year 2006 Nursing Education Loan Repayment Program.*—Of the 4,222 applicants, 615 awards were made (373 initial 2-year awards and 242 amendment awards). This translates to 14.6 percent of applicants receiving awards.
- Fiscal Year 2005 Nursing Scholarship Program.*—This program received 3,482 applicants and was able to provide 212 awards or 6.1 percent of the applicants received scholarships.
- Fiscal Year 2006 Nursing Scholarship Program.*—3,320 applicants were received and 218 awards made or 6.6 percent of the applicants received scholarships.

The ANSR Alliance requests that the subcommittee provide a minimum of \$200 million in fiscal year 2008 to fund the Title VIII—Nursing Workforce Development Programs. We also urge the restoration of the Advanced Education Nursing program (sec. 811) funded at a level on par with the proposed fiscal year 2008 increase for the other Title VIII programs.

This funding can be used to restore the Advanced Education Nursing program and fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications, as well as implement other essential endeavors to sustain and boost our Nation's nursing workforce. We thank you for consideration of our request.

#### SUMMARY

Programmatic area	Final fiscal year 2007	President's budget fiscal year 2008	ANSR Alliance request
Title VIII—Nursing Workforce Development Programs at HRSA .....	\$149,679,000	\$105,263,000	\$200,000,000

## ANSR ALLIANCE ORGANIZATIONS

Academy of Medical-Surgical Nurses; American Academy of Ambulatory Care Nursing; American Academy of Nurse Practitioners; American Association of Critical-Care Nurses; American Association of Nurse Anesthetists; American Association of Nurse Assessment Coordinators; American Association of Occupational Health Nurses; American College of Nurse Practitioners; American Organization of Nurse Executives; American Radiological Nurses Association; American Society for Pain Management Nursing; American Society of PeriAnesthesia Nurses; American Society of Plastic Surgical Nurses; Association of periOperative Registered Nurses; Association of Rehabilitation Nurses; Association of State and Territorial Directors of Nursing; Association of Women's Health, Obstetric and Neonatal Nurses; Emergency Nurses Association; Infusion Nurses Society; National Association of Clinical Nurse Specialists; National Association of Neonatal Nurses; National Association of Nurse Practitioners in Women's Health; National Association of Orthopaedic Nurses; National Association of Pediatric Nurse Practitioners; National Conference of Gerontological Nurse Practitioners; National Council of State Boards of Nursing, Inc.; National Gerontological Nursing Association; National League for Nursing; National Nursing Centers Consortium; National Nursing Staff Development Organization; National Organization for Associate Degree Nursing; National Organization of Nurse Practitioner Faculties; National Student Nurses' Association, Inc.; Society for Vascular Nursing; Society of Pediatric Nurses; Society of Trauma Nurses; and Society of Urologic Nurses and Associates.

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PREPARED STATEMENT OF THE ASSOCIATION OF ACADEMIC HEALTH SCIENCES  
LIBRARIES AND THE MEDICAL LIBRARY ASSOCIATION

## SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2008

(1) A 6.7 percent increase for the National Library of Medicine at the National Institutes of Health and support for the National Library of Medicine's Urgent Facility construction needs.

(2) Continued support for the Medical Library community's role in the National Library of Medicine's Outreach, Telemedicine, Disaster Preparedness and Health Information Technology Initiatives.

Mr. Chairman, thank you for the opportunity to testify today on behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) regarding the fiscal year 2008 budget for the National Library of Medicine (NLM). I am Marianne Comegys, Director of the Louisiana State University (LSU) Health Sciences Center Library in Shreveport, Louisiana.

MLA is a nonprofit, educational organization with more than 4,500 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research and works with a global network of partners to promote the importance of quality information for improved health to the healthcare community and the public.

AAHSL is comprised of the directors of the libraries of 142 accredited American and Canadian medical schools belonging to the Association of American Medical Colleges (AAMC). AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health professionals is trained in information-seeking skills that enhance the quality of healthcare delivery.

Together, MLA and AAHSL address health information issues and legislative matters of importance through a joint task force.

With respect to NLM's budget for the upcoming year, I would like to touch briefly on five issues: (1) the growing demand for NLM's basic services, (2) NLM's outreach and education services, (3) NLM's role in emergency preparedness and response, (4) NLM's health information technology initiatives and (5) NLM's facility needs.

## THE GROWING DEMAND FOR THE NLM'S BASIC SERVICES

Mr. Chairman, it is a tribute to NLM that the demand for its services and expertise continues to grow. As the world's foremost digital library and knowledge repository in the health sciences, NLM provides the critical infrastructure in the form of data repositories and integrated services such as GenBank and PubMed that are helping to revolutionize medicine and advance science to the next important era—individualized medicine based on an individual's unique genetic differences.

As the world's largest and most comprehensive medical library, services based on NLM's traditional and electronic collections continue to steadily increase each year.

These collections stand at more than 8.5 million items—books, journals, technical reports, manuscripts, microfilms, photographs, and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare.

Mr. Chairman, simply stated NLM is a national treasure and support for its programs and services could not be more important at the present time. I can tell you that without NLM our Nation's medical libraries would be unable to provide the quality information services that our Nation's health professionals, educators, researchers and patients have all come to expect.

Recognizing the invaluable role that NLM plays in our healthcare delivery system, MLA and AAHSL join with the Ad Hoc Group for Medical Research in asking for a 6.7 percent increase for NLM, and the NIH overall, in fiscal year 2008.

#### OUTREACH AND EDUCATION

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general public about NLM's services.

NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public.

We applaud the success of NLM's outreach initiatives, particularly those initiatives that reach out to medical libraries and health consumers. We ask the committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in fiscal year 2008.

#### *Partners in Information Access*

NLM's "Partners in Information Access" program is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well-positioned to ensure that every public health worker has electronic health information services that can protect the public's health. My own facility, the LSU Health Sciences Center in Shreveport, Louisiana, participates in this program. Through it, we are able to train public health workers on how to access health information online.

#### *PubMed/Medline*

NLM's PubMed/Medline is the Nation's premier online bibliographic database. PubMed/Medline makes accessing important medical information easier and quicker, which in turn lowers healthcare costs while improving care. For more than 10 years, PubMed/Medline has afforded anyone with access to the Internet the opportunity to tap into the vast resources of NLM.

The NIH Public Access policy makes use of NLM's PubMed Central electronic archive of full-text journal articles and manuscripts. This policy supports NLM's mission to archive and enhance access to healthcare information. We are concerned however that the current rate of participation in the voluntary policy is low. Even with an increasing number of journals depositing their complete contents in PubMed Central less than 15 percent of NIH-funded articles are available to the public there.

We concur with the NLM Board of Regents that the NIH Public Access policy cannot achieve its stated goals unless the deposit of manuscripts becomes mandatory. An informal survey conducted by AAHSL of faculty and research administrators at 19 universities illustrated that NIH-funded researchers are aware of the NIH Public Access policy. This finding has been confirmed by NIH focus groups. Hence, lack of awareness does not appear to be the primary reason for the low submission rate; rather lack of incentive is impeding the success of this policy.

In September, NLM, NIH and the Friends of NIH, launched NIH MedlinePlus Magazine. This new publication will be distributed in doctors' waiting rooms, and will provide the public with access to high quality, easily understood health information.

NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus "information prescriptions" to their patients. This initiative has been expanded to encourage genetics counselors to prescribe the use of NLM's Genetics Home Reference website. "Go Local" is another new exciting feature of MedlinePlus that enables local and State agencies and oth-

ers to participate by creating sites that link the MedlinePlus information seeker to local pharmacies, doctors and other health and social services. This service further enhances the value of NLM and MedlinePlus, not just for medical librarians and health professionals, but also for health consumers. It also provides a platform for enhancing public access to the information needed to prepare for and respond to disasters and emergencies.

#### *Clinical Trials*

NLM's clinical trials database was launched in February 2000 and lists more than 38,000 United States and international trials for a wide range of diseases. The clinical trials database is a free and invaluable resource to patients and families who are interested in participating in cutting-edge treatments for serious illnesses. MLA and AAHSL thank NLM for its leadership in creating ClinicalTrials.gov and looks forward to assisting NLM in advancing this important initiative.

We are aware of current proposals to mandate the submission of clinical trial results to this or a related database. We strongly endorse the notion of improving public access to information about the results of clinical trials, but are concerned about the possibility of results being posted without having been subject to some form of external review. If such information is to be used by patients and their physicians to make informed decisions, the information must be trustworthy and should be held to the same standard as other publicly available information made available on the NLM web sites.

#### EMERGENCY PREPAREDNESS AND RESPONSE

MLA and AAHSL support the recommendation of the NLM Board of Regents Long Range Plan for 2006–2016 that NLM establish a Disaster Information Management Research Center to expand NLM's capacity to support disaster response and management initiatives. Following Hurricane Katrina, NLM provided health professionals and the public with access to needed health and environmental information by: (1) quickly compiling Web pages on toxic chemicals and environmental concerns, (2) rapidly providing funds, computers and communication services to assist librarians in the field who were restoring health information services to displaced clinicians and patients, and (3) rerouting interlibrary loan requests from the afflicted regions through the NNLM.

#### HEALTH INFORMATION TECHNOLOGY AND BIOINFORMATICS

Mr. Chairman, NLM has played a pivotal role in creating and nurturing the field of medical informatics, most notably through the creation of GenBank and a wide array of related scientific data and analysis tools which provide critical infrastructure for the Nation's researchers. This critical infrastructure will be key to advances in medicine in the future.

For nearly 35 years, NLM has supported informatics research and training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country, and many of the country's exemplary electronic health record systems benefited from NLM grant support.

A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free United States-wide use (e.g., SNOWMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records.

MLA and AAHSL encourage Congress to continue their strong support of NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also support Health Information Technology initiatives at

ONCHIT and the Agency for Healthcare Research and Quality (AHRQ) that build upon initiatives housed at NLM.

#### NLM'S FACILITIES NEEDS

Mr. Chairman, over the past two decades NLM has assumed many new responsibilities, particularly in the areas of biotechnology, health services research, high performance computing and consumer health. As a result, NLM has had tremendous growth in its basic functions related to the acquisition, organization and preservation of an ever-expanding collection of biomedical literature an expanded staff. NLM now houses 1,100 staff in a facility built to accommodate only 650. This increase in the volume of biomedical information and in the number of personnel has

led to a serious space shortage. Digital archiving—once thought to be a solution to the problem of housing physical collections—has only added to the challenge, as materials must often be stored in multiple formats and as new digital resources consume increasing amounts of storage space. As a result, the space needed for computing facilities has also grown, further squeezing out staff. In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. Further, Senate Report 108-345 that accompanied the fiscal year 2005 appropriations bill acknowledged that the design for the new research facility at NLM had been completed and the committee urged the NIH to assign a high priority to this construction project so that NLM's information-handling capabilities are not jeopardized.

We encourage the subcommittee to provide the resources necessary to construct a new facility.

Mr. Chairman, thank you again for the opportunity to present the views of the medical library community.

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#### PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 89 of the Nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration as the Labor, Health and Human Services Appropriations Subcommittee plans the fiscal year 2008 appropriations for the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

#### CANCER BURDEN

In 2007, there will be approximately 1.44 million new cases of cancer in the United States.<sup>1</sup> Today, lifetime cancer risk in the United States is one in two for men and one in three for women.<sup>2</sup> This number will continue to climb as the population ages, with an estimated 18.2 million cancer survivors (those undergoing treatment, as well as those who have completed treatment) alive in 2020. By comparison, 11.7 million survivors were living in the United States in 2005.<sup>3</sup>

#### RESEARCH IN JEOPARDY

A recent analysis published in the *Journal of Oncology Practice* suggested that the increase in the number of cancer patients and survivors over the next decade will be coupled with a shortage of clinical oncologists.<sup>3</sup> And there is another shortage that is all too real now, the implications of which will be felt for generations to come if our government's policymakers do not address the problem immediately. Because of continuing decreases to the budgets of the NIH and NCI (in actual dollars and as a result of biomedical inflation), grants to support cancer researchers as they discover new treatments for cancer and strategies to prevent and detect the disease continue to be cut. Without these grants, fewer and fewer cancer researchers will be able to maintain their commitment to science—a dearth of cancer researchers is on the horizon.

#### CANCER RESEARCH: BENEFITING ALL AMERICANS

The cancer research enterprise in the United States is second-to-none. Cancer research, conducted in academic laboratories across the country saves money by reducing healthcare costs associated with the disease, enhances the United States' global competitiveness, and has a positive economic impact on localities that house a major research center. While these aspects of cancer research are important, what cannot be overstated is the impact cancer research has had on individuals' lives—lives that have been lengthened and even saved by virtue of discoveries made in cancer research laboratories across the United States.

Our Nation's cancer researchers are making advances against this disease—for the second year in a row, statistics show that the number of people dying of cancer has declined.<sup>2</sup> And for the first time ever, coming generations may be able to prevent some cancers from occurring at all. For instance, with the recent FDA approval of the HPV (human papillomavirus) vaccine Gardasil, young women will be protected against the virus that causes up to 70 percent of cervical cancer cases world-

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<sup>1</sup> Cancer Statistics, 2007. CA: Cancer Journal for Clinicians 2007; 57: 43–66.

<sup>2</sup> The Nation's Investment in Cancer Research; A Plan and Budget Proposal for Fiscal Year 2008, National Cancer Institute, 2007.

<sup>3</sup> Future Supply and Demand for Oncologists, *Journal of Oncology Practice* 2007; 3(2): 79–86.

wide.<sup>4</sup> In 2007 11,150 women will develop cervical cancer and 3,670 will die as a result of the disease.<sup>5</sup> Gardasil is expected to significantly reduce the number of cases of cervical cancer as young women begin receiving the vaccine. Also, the HPV infection may play some role in the development of other diseases such as head and neck cancer, suggesting that the vaccine may have wider applicability in the future.

Recent headlines have linked dropping breast cancer rates with a decrease in the use of hormone replacement therapy among millions of older women. An NCI-funded study conducted at The University of Texas M.D. Anderson Cancer Center explored factors that may be involved in the 7 percent age-adjusted decline—or 14,000 fewer cases—in breast cancer incidence between 2002 and 2003.<sup>6</sup> The researchers, led by Dr. Donald Berry, concluded that “only the potential impact of hormone replacement therapy was strong enough to explain the effect.”<sup>2</sup> Without a strong research infrastructure to examine this relationship, health professionals might still routinely prescribe menopausal hormones without knowing that the hormones may increase their patients’ risk of developing breast cancer.

This and other success stories are positive news in the war on cancer, but are only one small part of the battle. Research advances that have led to increased cancer survivorship, prevention efforts, and enhanced treatment and understanding of the disease are at stake with research funding becoming more and more limited. Now is the time to provide funding to NIH and NCI to fully capitalize on the accelerated pace of research that was fostered by the doubling of the NIH budget from 1998 through 2003, not to risk losing out on lifesaving opportunities by cutting funding to the Nation’s biomedical infrastructure.

#### EFFECTS OF THE “UNDOUBLING” OF THE NIH BUDGET

During the period from 1998 through 2003 the budget of the NIH was doubled. This doubling provided resources that allowed a greater number of promising young investigators to enter the field of cancer research, and also supported research into the ideas of established investigators. In 2007, however, funding for NIH is in the process of being “undoubled” through actual budget cuts and because of the effects of biomedical inflation. This year, NIH’s budget is approximately \$28.9 billion—an impressive sum to be sure. However, if NIH’s 2003 budget (the last year of the doubling period) had been increased each year only to account for biomedical inflation, its 2007 budget would be \$31.6 billion.

While the doubling of the NIH budget was an ambitious undertaking, the effort has ultimately resulted in inconsistent funding for the institutes that make up the NIH. The budget of the NCI alone has lost approximately 12 percent of its purchasing power due to the effects of biomedical inflation.<sup>7</sup> The Biomedical Research and Development Price Index (BRDPI) is calculated each year to determine how NIH expenditures must increase to compensate for inflation. In 2005 BRDPI was estimated at 3.9 percent, meaning that each research dollar lost 3.9 percent of its value for the year.<sup>8</sup> The NIH budget also decreased 0.5 percent from 2005 to 2006, which caused a net loss of 4.4 percent purchasing power for 2006. NCI Director Dr. John E. Niederhuber estimates that because of actual cuts in funding and the effects of BRDPI, in fiscal year 2006 NCI was unable to fund 180 grants that would otherwise have been deemed worthy of funding.<sup>7</sup> These projects would have built upon progress made during the doubling period—progress that will now be unrealized.

In 2007, NCI’s Clinical Trials Cooperative Group Program will have to cut as much as 60 percent of its members’ new clinical trials. This will result in an 11 percent decrease in the number of patients accrued into clinical trials, or approximately 3,000 eligible patients who will be unable to enroll in a cooperative group trial.<sup>7</sup> These trials would answer questions that help lead to more effective therapies and other interventions for cancer, as well as methods for screening and prevention. Not only will these patients be unable to benefit from the cutting-edge treatments available only through clinical trials, patients for generations to come will not benefit from the results of this research.

<sup>4</sup>Taking Pride in an Important Achievement, The NCI Cancer Bulletin, 2006; 3(24): 1–2.

<sup>5</sup>American Cancer Society. Cancer Facts & Figures 2007, 2007, 20–21.

<sup>6</sup>Decline in Breast Cancer Cases Likely Linked to Reduced Use of Hormone Replacement. M.D. Anderson Cancer Center News Release, December 14, 2006.

<sup>7</sup>Cancer Research Budget Cuts Cause “Missed Opportunities,” NCI Director Tells Advisors, The Cancer Letter; 33(9), 5–8.

<sup>8</sup>Biomedical Research and Development Price Index (BRDPI), BRDPI Table of Annual Values Index. Office of Budget, National Institutes of Health, 2007. [http://officeofbudget.od.nih.gov/ui/GDP\\_FromGenBudget.htm](http://officeofbudget.od.nih.gov/ui/GDP_FromGenBudget.htm)

Additionally, NCI's Specialized Programs of Research Excellence (SPORes) program that promotes interdisciplinary research to move basic research findings from the laboratory to clinical settings was cut by 8 percent, or \$8 million, in fiscal year 2006, with more cuts expected this year. NCI's Tobacco Control Research Branch has been cut by \$6.5 million between fiscal year 2004 and fiscal year 2007 and its Cancer Survivorship Program by \$1 million. Patient accrual for clinical trials at NCI's Center for Cancer Research (CCR) was at 4,210 in fiscal year 2004, but in fiscal year 2006 that number was down to 3,795.<sup>7</sup>

#### THE NATION'S CANCER CENTERS

The nexus of cancer research in the United States is the Nation's network of cancer centers, both with and without NCI designation, that are represented by AACI. These cancer centers are highly integrated, multidisciplinary hubs of scientific excellence and exceptional patient care. They are uniquely patient oriented, research intensive, translationally adept, and clinically superb. In 2005, these academic based institutions received 86 percent of the grant dollars available for 2005, or 59 percent of NCI's budget as a whole. Because these centers are networked nationally, opportunities for collaborations are many—assuring wise and non-duplicative investment of scarce Federal dollars.

In addition to conducting basic, clinical, and population research, the cancer centers are largely responsible for training the cancer workforce that will practice in the United States in the years to come. Much of this training is dependent on Federal dollars, via training grants and other funding from NCI. Decreasing Federal support will significantly undermine the centers' ability to continue to train the next generation of cancer specialists—both researchers and providers of cancer care.

Success stories at the cancer centers are common—but are in danger of becoming less so as research dollars are lost. For instance, a patient at a major academic cancer center had been told he had 6 months to live after being diagnosed with an aggressive form of brain cancer. But through an innovative clinical trial at the center, this patient was tumor-free 6 years later.<sup>9</sup> Without the Federal funding that supported his treatment, he may not have been so fortunate.

#### FINANCIAL IMPACT ON CANCER CENTERS

The cancer center network in the United States forms the country's cancer research infrastructure. As the nationwide hubs of cancer-related scientific inquiry, the negative impact of reduced Federal funding for cancer research on these centers is enormous. The rapid pace of cancer research at AACI centers requires that investigators and clinicians from diverse disciplines work together to share information, expertise and resources. These interactions yield many insights into the cancer problem. Reduced, or—even worse—no support for even one member of this multidisciplinary team affects the collective progress and productivity of the entire program.

Furthermore, the grants that comprise the core funding for the NCI-designated cancer centers have been flat for the past 3 years.<sup>7</sup> This core funding helps support academic and research institutions to sustain coordinated interdisciplinary programs in cancer research. With no annual adjustment for inflation, the actual purchasing power over the course of a typical multi-year grant has decreased, essentially resulting in a cut to funding. Stagnant funding prevents expansion at existing centers, but also—and perhaps more importantly—prevents new centers from achieving NCI designation. While most major metropolitan areas in the United States have easy access to an NCI-designated cancer center, several States and many underserved areas do not.

#### SOCIAL VALUE

Though cancer statistics can seem daunting, even small steps forward will have tremendous results. Dr. Kevin M. Murphy, the George J. Stigler Distinguished Service Professor of Economics at the University of Chicago Graduate School of Business, estimates that even a 1 percent reduction in cancer deaths would result in almost \$500 billion in social value to the United States. Social value is calculated in terms of improved health and longevity. Curing the disease would be worth as much as \$50 trillion in social value.<sup>10</sup>

<sup>9</sup>Road to Nowhere, *Frontiers Magazine*, Winter 2006.

<sup>10</sup>AACR Meeting: Increase Research Funding that Cuts U.S. Cancer Mortality by 1 percent Could Provide Payback of Nearly \$500 Billion, *Oncology Times*, May 10, 2006.

## CONCLUSION

These are very exciting times in science and, particularly, in cancer research. Recent discoveries in the molecular biology of cancer have led to important advances and new approaches to the prevention and treatment of the disease. Drug discovery often is now based on the understanding of molecular targets unique to cancer cells compared with normal cells. Because of the Nation's investment in this research, we are learning how to target and treat cancer specifically, while sparing healthy tissues, and we are helping survivors lead more vibrant lives. Reduced or flat funding will have a grave impact on progress in targeted therapies and other promising research endeavors that could lead to increased cancer survivorship.

Simply put, cancer research is a marathon, not a sprint. While the period of NIH doubling briefly helped speed the pace of cancer research, the potential legacy of this doubling will be squandered if the NCI and NIH budgets are not funded—at a minimum—to account for the effects of biomedical inflation. AACI and its members urge Congress to support an NIH budget increase for fiscal year 2008 of at least 6.7 percent to make up for recent annual inflationary shortfalls. AACI and its members also urge Congress to appropriate \$5.1 billion for NCI's fiscal year 2008 budget, which reflects a 6.7 percent increase over fiscal year 2007, consistent with our overall NIH request.

We must, as a Nation, commit to fully funding the budget of the NCI and the NIH. Our generation has been fortunate—a diagnosis of cancer is no longer the certain death sentence it was for our parents and grandparents. We owe the same to our children and grandchildren, and we urge your support to increase this critical funding.

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 PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN PUBLISHERS

I am pleased to submit the following statement for the record on behalf of the Professional and Scholarly Publishing Division of the Association of American Publishers (PSP/AAP) in conjunction with the subcommittee's hearing on the fiscal year 2008 Budget for the National Institutes of Health (NIH). The AAP represents commercial and non-profit entities who publish scientific, technical and medical journals. Scholarly publishers are committed to working with NIH to successfully implement NIH's Public Access Policy and ensure that articles based on NIH-funded research are deposited with NIH. Publishers believe that such a proactive public-private partnership between NIH and journal publishers is critical to the success of the NIH policy. As a result of the voluntary efforts by publishers, the number of articles deposited with NIH has increased significantly.

The number of articles deposited with NIH has increased well beyond the low figures referenced by NIH. The voluntary effort initiated by publishers to deposit manuscripts on behalf of authors has resulted in an increase in deposits from 4 percent to over 20 percent. This significant increase is just the beginning. We will be able to do more as additional publishers join this effort. However, we need NIH's help to make that happen. To date, NIH has been slow to work with publishers to resolve key implementation issues necessary to bring on additional publishers.

We strongly oppose any move to a mandatory policy and feel that NIH should instead engage publishers more broadly so we may achieve our mutual objectives. This is important to attain the maximum article deposition rate without adversely affecting the valuable peer review process or the stability of important scientific journals and their publishers. Considering the immense stakes, it is prudent to work through the outstanding issues under the voluntary policy in a way that optimizes participation by all players to ensure the greatest benefit to the public interest and scientific progress.

We are confident that through a cooperative approach involving the publishing community, deposition rates for manuscripts reporting on NIH-funded research can reach optimum levels within a period of month, not years. We encourage Congress to direct NIH to work together with publishers to improve the implementation of the voluntary Public Access Policy and further increase deposit rates. We stand ready to work with NIH to achieve this important goal.

Publishers remain committed to working with NIH to ensure the successful implementation of the current voluntary program, while protecting the peer review process that helps ensure the quality and integrity of scientific and medical research. On behalf of the AAP, I appreciate this opportunity to submit this statement and look forward to enhanced collaboration with NIH.

## PREPARED STATEMENT OF THE ASSOCIATION FOR CLINICAL RESEARCH TRAINING

## SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

A 6.7 percent increase for the National Institutes of Health, including the National Center for Research Resources.

\$462 million for the Clinical and Translational Science Awards.

\$350 million for the agency for Healthcare Research and Quality.

\$750 million for a Center for Comparative Effectiveness at the agency for Healthcare Research and Quality. Of this \$750 million, a substantial portion should be for research training.

The Association for Clinical Research Training (ACRT) is committed to improving the Nation's health by increasing the amount and quality of clinical research through the expansion and improvement of clinical research training. This training is funded by both the National Institutes of Health (NIH) and the Agency for Healthcare Research and Quality (AHRQ).

## NATIONAL INSTITUTES OF HEALTH

The NIH's Clinical and Translational Science Awards (CTSAs) aim to meet one of the profound challenges of 21st Century medicine, namely that the ever increasing complexities involved in conducting clinical research are making it more difficult to translate new knowledge from the bench to the bedside. As Dr. Elias Zerhouni, the Director of the NIH, wrote in the October 13, 2005 edition of the New England Journal of Medicine, "it is the responsibility of those of us involved in today's biomedical research enterprise to translate the remarkable scientific innovations we are witnessing into health gains for the Nation."

The CTSAs assist institutions in creating a home for clinical and translational science that has the resources necessary to train and advance a cadre of investigators. The CTSAs transform basic research into clinical practice, advance information technology, integrate research networks and improve workforce training.

The ACRT supports the fiscal year 2008 President's budget request of \$462 million for the CTSAs, and joins the Ad Hoc Group for Medical Research in asking for a 6.7 percent increase in fiscal year 2008 for the NCRR and the NIH overall.

## AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

AHRQ is the lead Federal agency charged with supporting research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, eliminate disparities and broaden access to essential services. AHRQ supports health services research that will improve the quality of healthcare and improve evidence-based decision making. The agency also transforms research into practice in order to facilitate wider access to effective healthcare services.

By providing funds to train clinical researchers, AHRQ ensures that there continues to be researchers who are able to provide the Nation with high quality, unbiased information about healthcare. Once consumers have this information, they will then be able to make effective, evidence based healthcare choices. A Center for Comparative Effectiveness would help to leverage AHRQ's expertise in providing this information to consumers. But in order to continue AHRQ's mission of training clinical researchers, there must be ample funding for training the investigators who will move this center forward.

The ACRT joins the Friends of AHRQ in requesting \$350 million for AHRQ in fiscal year 2008. The ACRT also joins the Society of General Internal Medicine (SGIM) and other organizations in advocating for a Center for Comparative Effectiveness at AHRQ. This center should have an initial investment of \$750 million, including a substantial portion for research training.

## PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

Mr. Chairman and members of the subcommittee, I am pleased to submit testimony on behalf of the Association of Maternal and Child Health Programs (AMCHP) regarding the critical need for increased funding of the Maternal and Child Health Services Block Grant, Title V of the Social Security Act. The Maternal and Child Health Services Block Grant is the only Federal program devoted to improving the health of all women, children and families. The program provides funding to State maternal and child health programs, which serve 33 million women and children in the United States.

When our children are healthy, they are more likely to succeed. Maternal and child health (MCH) programs help promote our children's success by identifying emerging and urgent health needs, while continuing to assure services like prenatal care, universal newborn screening, immunizations and access to health services. In fact, 80 percent of all American children access or connect with one or more programs funded by the Title V MCH Block Grant, making this program a vital resource for families—especially those with special health care needs.

#### INCREASE THE BLOCK GRANT TO \$750 MILLION

*The MCH Block Grant "Works."*—The Office of Management and Budget reported that the block grant-funded programs helped to decrease the infant mortality rate, prevent disabling conditions, increase the number of children immunized, increase access to care for uninsured mothers and children, and improve the overall health of all mothers and children. Funding for the program has decreased since fiscal year 2002, yet participation has increased. These funding shortages have threatened the MCH programs' ability to continue achieving successful outcomes. As health care costs rise and the number of under- or un-insured women and children continue to grow, block grant programs will face a critical erosion of their successes. This erosion will impact the health and well-being of hundreds of thousands of women and children.

*The Need for Programs for Families and Children With Special Health Care Needs Continues to Grow.*—As States face economic hardships and limit their enrollment and benefit packages in Medicaid and State Children's Health Insurance Programs (CHIP), more women and children seek and receive services through MCH programs. This is especially true for children with special health care needs who require services that are not covered in most health insurance plans. Block grant funds also are used to reduce infant mortality, provide mental health care, improve oral health, provide care coordination to children with special health care needs and reduce racial disparities in health care.

*The Block Grant Funds Improvements to Vital Health Care Systems.*—State MCH programs establish health care standards that promote preventive health care; provide outreach and health care education to assure that children receive services through insurance programs; and, measure the impact of health care practices. The block grant allows States to fund efforts to increase the quality health care, collect data and conduct analyses. MCH programs identify factors associated with infant mortality, inadequate immunizations, and late prenatal care so that strategies can be developed to address these needs. Every funding cut means the provision of fewer direct services and limits the development of health care system improvements.

#### MATERNAL AND CHILD BLOCK GRANT-FUNDED PROGRAMS HAVE FAR-REACHING IMPACT AND USE MONIES EFFICIENTLY AND EFFECTIVELY

##### *Working with Efficiency and Agility, Spending Limited Resources Wisely*

The care coordination of MCH programs ensures that all mothers and children, insured, under- and un-insured, utilize available health care coverage to receive all possible benefits. All payment sources (private insurance, State or federally funded health care) are integrated to deliver quality care.

Dollars invested in MCH programs yield a high return on investment.

The State of Iowa was awarded an Early Hearing Detection and Intervention grant through 2008 to focus on reducing the number of infants who are "lost" in the system, delaying the provision of early intervention services. The States' Child Health Specialty Clinics use the funds to screen all newborns and enroll eligible children into early intervention programs.

The Pennsylvania Department of Health currently funds the Pennsylvania Shaken Baby Syndrome Prevention and Awareness Program in the amount of approximately \$100,000 annually. This program seeks to increase awareness of new parents on the dangers of shaking a baby. Medical care over the lifetime of a single child that suffers from Shaken Baby Syndrome can easily surpass the million dollar mark.

In Florida, for every dollar spent on newborn screening, \$17 are saved. Newborn screening detects diseases and disorders that, without intervention, are debilitating, costly and potentially deadly.

##### *Focusing on Those with the Greatest Need*

Nationally, the incidence of low birth weight babies and infant mortality for African Americans is twice the rate for whites. MCH programs share strategies and tactics to reduce these racial and ethnic disparities.

Nevada contracts with local agencies to serve uninsured pregnant women with prenatal care including screening and referral for depression during and post-pregnancy.

Many young people are at risk for serious chronic diseases and premature death. Among 5- to 24-year-olds, nearly 75 percent of deaths are behavior-related, as are many illness and social problems, such as substance abuse. State MCH programs work to build the capacity of adolescent health coordinators and child health professionals at the State level to address adolescent health and make it a priority.

State technical assistance programs funded by the Title V MCH Block Grant help prevent HIV transmission from mothers to babies, help women quit smoking during pregnancy and promote safe motherhood.

A recent survey of State MCH program adolescent health coordinators identified teen pregnancy prevention as the number one priority related to adolescent health. State MCH programs work to raise the visibility of teen pregnancy prevention efforts to increase State capacity to address teen pregnancy and develop sustained and effective prevention efforts.

#### *Serving America's Families*

MCH State programs serve more than 33 million people, striving to improve the health of all women, infants, children and adolescents including those with special health care needs by delivering critical screening services, and supporting preventive, primary and specialty care.

Montana's MCH funding was the financial basis for public health services, especially in many small counties until recent bioterrorism funding. Federal and State MCH funding enables local public health to leverage small amounts of match funding at the county level.

Eighty percent of America's children utilize one or more maternal and child health program.

California's MCH program is collaborating with the Children's Hospital of Los Angeles and State Epilepsy Foundation on a HRSA grant called Improving Access to Care for Children and Youth with Epilepsy. The overall goal is to improve access to health and other services and supports related to epilepsy by facilitating the development of state-wide community-based interagency models of comprehensive, family-centered and culturally effective statewide standards of care. The program collaborates with Family Voices and the Children's Regional Integrated Service Systems which comprises 14 MCH county programs to implement integrated community systems of care for children and youth with special health care needs.

More families are turning to MCH services. Over the last 5 years, the number of individuals served increased by 18 percent.

The number of families served through Regional Genetics Clinics in Washington State grew from 2,736 families to 4,406 families in 5 years.

#### *Touching the Lives of Women and Children from Every Walk of Life*

MCH clients are as diverse as the country itself. MCH programs serve families in urban, suburban, rural, and frontier settings.

Many MCH clients are "special populations," those that face severe health problems and access issues to needed health care. They include children with complex health care needs, the under- and uninsured, American Indian and Alaska Natives, migrant and seasonal workers, immigrants, and racial and ethnic minorities.

Pennsylvania's MCH program has partnered with the Pennsylvania Chapter of the American Academy of Pediatrics on the Educating Practices in Community Integrated Care (EPIC-IC) Medical Home Training Program. Between Oct. 2006 to Feb. 2007, the EPIC IC program has prevented over 200 hospitalizations and almost 700 emergency doctor visits from. Future cost benefit modeling with parent and insurance data can translate this savings into real time dollars. In addition, care coordination and the EPIC IC program has favorably impacted the quality of life of both parents and children and youth with special health care needs by preventing almost 400 missed school days and over 250 parental work days missed.

MATERNAL AND CHILD HEALTH PROGRAMS WORK HAND IN HAND WITH MEDICAID AND SCHIP. THE HEALTH AND CONTINUITY OF OUR PROGRAMS ARE VITAL TO THEIR CONTINUED EFFECTIVENESS

AMCHP represents the State public health leaders and others working to assure that all women, children and families receive quality health care. MCH programs provide services and supports that augment Medicaid and SCHIP coverage and ensure eligible women and children access to needed services. MCH programs work

with other programs such as WIC, community health providers, Head Start and schools to make referrals to Medicaid and SCHIP programs. They also train public health workers who inform families about the availability of Medicaid and SCHIP and how to apply. These programs participate in the development of Medicaid and SCHIP policies and practice standards that help providers work with special populations, such as children and youth with special health care needs.

Changes to Medicaid and SCHIP often have a great effect on MCH programs and the people they serve. As some States restrict eligibility for Medicaid and SCHIP, people in need look to MCH-funded services to meet their health care needs. This puts an increased demand on MCH programs to offer more services without additional funding. With the increasing cost of health care and tighter State budgets, States are examining ways to offer health care services with decreasing resources. It is more important than ever to maintain the necessary services for pregnant women, children and adolescents by using the expertise, creativity and resources of Medicaid, SCHIP and Title V in joint program planning and development.

#### CONCLUSION

After its creation, the Title V Maternal and Child Health Block Grant grew from a \$2.7 million program in fiscal year 1936 to a \$731 million program in fiscal year 2002 to address the developing needs of America's women and children. However, since then, as maternal and child health related needs have increased, the Block Grant funding has decreased. Title V remains vital as a source of flexible funding that allows States to meet the needs of their most vulnerable populations through effective, efficient and integrated programs. Increased funding is crucial to sustain and expand these efforts to assure quality health care for families and children with special health care needs.

Please provide \$750 million for the Block Grant in fiscal year 2008. Thank you for this opportunity to provide testimony.

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#### PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

##### SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

\$300 million for the Title VII Health Professions Training Programs, including:  
 —\$33.6 million for the minority centers of excellence.  
 —\$35.6 million for the health careers opportunity program.  
 \$250 million for the National Institutes of Health's National Center on Minority Health and Health Disparities.  
 Support for the National Center for Research Resources Extramural Facilities Construction program.  
 —\$6.7 percent increase for Research Centers for Minority Institutions.  
 —\$119 million for extramural facilities construction.  
 \$65 million for the Department of Health and Human Services' Office of Minority Health.  
 \$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions program.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Barbara Hayes, president of the Association of Minority Health Professions Schools (AMHPS) and the dean of the school of pharmacy at Texas Southern University. AMHPS, established in 1976, is a consortium of our Nation's 12 historically black medical, dental, pharmacy, and veterinary schools. The members are two dental schools at Howard University and Meharry Medical College; four schools of medicine at The Charles Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy at Florida A&M University, Hampton University, Howard University, Texas Southern University, and Xavier University; and one school of veterinary medicine at Tuskegee University. In all of these roles, I have seen first-hand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, our Nation's health professions workforce

does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help AMHPS continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals, like the AMHPS members, have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 and fiscal year 2007 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

In fiscal year 2008, funding for the Title VII Health Professions Training programs must be restored to the fiscal year 2005 level of \$300 million, with two programs—the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs)—in particular need of a funding restoration. In addition, the National Institutes of Health (NIH)'s National Center on Minority Health and Health Disparities (NCMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), are both in need of a funding increase.

#### *Minority Centers of Excellence*

COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs.

Presently the statute is configured in such a way that the "original four" institutions compete for the first \$12 million in funding, "Hispanic and Native American" institutions compete for the next \$12 million, and "Other" institutions can compete for grants when the overall funding is above \$24 million. For funding above \$30 million all eligible institutions can compete for funding.

However, as a consequence of limited funding for COEs in fiscal year 2006 and fiscal year 2007, "Hispanic and Native American" and "Other" COEs have lost their support. Out of 34 total COEs in fiscal year 2005, only 4 now remain due to the

cuts in funding. Many AMHPS institutions lost its COE funding as well, which was a devastating blow to our institutions.

For fiscal year 2008, I recommend a funding level of \$33.6 million for COEs.

#### *Health Careers Opportunity Program (HCOP)*

HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. If HCOPs continue to lose Federal support, then these numbers will drastically decrease. It is estimated that the number of minority students admitted to health professional schools will drop by 25–50 percent without HCOPs. A reduction of just 25 percent in the number of minority students admitted to medical school will produce approximately 600 fewer minority medical students nationwide.

As a result of cuts in the fiscal year 2006 and fiscal year 2007 Labor-HHS Appropriations process, only 4 out of 74 total HCOPs currently receive Federal funding.

For fiscal year 2008, I recommend a funding level of \$35.6 million for HCOPs.

#### NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES CONSTRUCTION

Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our Nation's research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is \$250 million. The law also includes a 25 percent set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. Finally, the law allows the NCRR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools.

Unfortunately, funding for NCRR's Extramural Facility Construction program was completely eliminated in the fiscal year 2006 Labor-HHS bill, and no funding was restored in the funding resolution for fiscal year 2007. In fiscal year 2008, please restore funding for this program to its fiscal year 2004 level of \$119 million, or at a minimum, provide funding equal to the fiscal year 2005 appropriation of \$40 million.

#### RESEARCH CENTERS IN MINORITY INSTITUTIONS

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2008.

#### STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS—DEPARTMENT OF EDUCATION

The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, section 326) is extremely important to AMHPS. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2008, an appropriation of \$65 million (an increase of \$7 million over fiscal year 2007) is suggested to continue the vital support that this program provides to historically black graduate institutions.

#### *National Center on Minority Health and Health Disparities*

The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NCMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued

development of faculty, labs, and other learning resources. The NCMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NCMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Minority Centers of Excellence program.

For fiscal year 2008, I recommend a funding level of \$250 million for the NCMHD.

*Department of Health and Human Services' Office of Minority Health*

Specific programs at OMH include:

- (1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
- (2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
- (3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
- (4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. Unfortunately, the OMH does not yet have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations.

For fiscal year 2008, I recommend a funding level of \$65 million for the OMH.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS's member institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. The Association seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

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PREPARED STATEMENT OF THE ASSOCIATION FOR PSYCHOLOGICAL SCIENCE

SUMMARY OF RECOMMENDATIONS

As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$30.8 billion for NIH in fiscal year 2008, a 6.7 percent increase.

APS requests committee support for establishing behavioral and social science research and training as a core priority at NIH in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.

Given the critical role of basic behavioral science research and training in addressing many of the Nation's most pressing public health needs, we ask the committee to (1) require NIMH to coordinate its efforts with other Institutes to ensure that these and related areas are adequately supported at NIH; and (2) request a report from NIH outlining a structure for basic behavioral science within NIGMS.

APS encourages the committee to review behavioral science activities at a number of individual institutes. Examples are provided in this testimony to illustrate the exciting and important behavioral and social science work being supported at NIH.

Mr. Chairman, members of the committee: As our organization's name indicates, APS is dedicated to all areas of scientific psychology, in research, application, teaching, and the improvement of human welfare. Our 18,000 members are scientists and educators at the Nation's universities and colleges, conducting NIH-supported basic and applied, theoretical and clinical research. They look at such things as: the connections between emotion, stress, and biology and the impact of stress on health; they look at how children grow, learn, and develop; they use brain imaging to explore thinking and memory and other aspects of cognition; they develop ways to manage debilitating chronic conditions such as diabetes and arthritis as well as depression and other mental disorders; and they address the behavioral aspects of smoking and drug and alcohol abuse. Still others look at how genes and the environment influence behavioral traits such as aggression and anxiety; the development of a normative model of vision to understand how it is used in behavior; and the study of the behavioral and neural mechanisms of sound localization.

As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$30.8 billion for NIH in fiscal year 2008, an increase of 6.7 percent over the fiscal year 2007 Joint Funding Resolution level. This increase would halt the erosion of the Nation's public health research enterprise, and help restore momentum to our efforts to improve the health and quality of life of all Americans.

Within the NIH budget, APS is particularly focused on behavioral and social science research and the central role of behavior in health. The remainder of this testimony concerns the status of those areas of research at NIH.

#### BASIC AND APPLIED PSYCHOLOGICAL RESEARCH RELATED TO HEALTH

Behavior is an indelible part of health. Many leading health conditions—heart disease; stroke; lung disease and certain cancers; obesity; AIDS, suicide; teen pregnancy, drug abuse and addiction, depression and other mental illnesses; neurological disorders; alcoholism; violence; injuries and accidents—originate in behavior and can be prevented or controlled through behavior. As just one example, stress is something we all feel in our daily lives, and we now have a growing body of research that illustrates the direct link between stress and health: chronic stress accelerates not only the size but also the strength of cancer tumors; mounting evidence indicates that chronic stressors weaken the immune system to the point where the heart is damaged, paving the way for cardiac disease; children who are genetically vulnerable to anxiety and who are raised by stressed parents are more likely to experience more anxiety and stress later in life; animal research has shown that stress interferes with working memory; and stressful interactions may contribute to systemic inflammation in older adults which in turn may maintain negative emotion and pain over time.

None of the conditions or diseases described above can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating and preventing them. Just as there exists a layered understanding, from basic to applied, of how molecules affect brain cancer, there is a similar spectrum for behavioral research. For example, before you address how to change attitudes and behaviors around AIDS, you need to know how attitudes develop and change in the first place. Or, to design targeted therapies for bipolar disorder, you need to know how to understand how circadian rhythms work as disruptions in sleeping patterns have been shown to worsen symptoms in bipolar patients.

Despite the clear central role of behavior in health, behavioral research has not received the recognition or support needed to reverse the effects of behavior-based health problems in this Nation. APS asks that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, by encouraging NIH to advance a model of health that includes behavior in its scientific priorities, and by encouraging stable support for basic behavioral science research at NIH.

#### BASIC BEHAVIORAL SCIENCE RESEARCH NEEDS A STABLE INFRASTRUCTURE

Broadly defined, behavioral research explores and explains the psychological, physiological, and environmental mechanisms involved in functions such as memory, learning, emotion, language, perception, personality, motivation, social attachments, and attitudes. Within this, basic behavioral research aims to understand the fundamental nature of these processes in their own right, which provides the foundation for applied behavioral research that connects this knowledge to real-world concerns such as disease, health, and life stages. We are sorry to have to tell you that basic behavioral research is not faring well at NIH, a circumstance that jeopardizes the success of the entire behavioral research enterprise. Let us describe the current situation:

Traditionally, the National Institute of Mental Health (NIMH) has been the home for far more basic behavioral science than any other institute. Many basic behavioral and social questions were being supported by NIMH, even if their answers could also be applied to other institutes. Recently, NIMH has begun to aggressively reduce its support for many areas of the most basic behavioral research, in favor of translational and clinical research. This means that previously funded areas now are not being supported.

NIMH's abrupt decision to narrow its portfolio came without adequate planning and is happening at the expense of critical basic behavioral research. We favor a broader spectrum of support for basic behavioral science across NIH as appropriate and necessary for a vital research enterprise. But until other Institutes have the capacity to support more basic behavioral science research connected to their missions, programs of research in fundamental behavioral phenomena such as cognition, emotion, psychopathology, perception, and development, will continue to lan-

guish. The existing conditions for basic behavioral science research undermine the scientific community's efforts to address many of the Nation's most pressing public health needs. We ask the committee to require NIMH to coordinate its efforts with other Institutes to ensure that these areas are adequately supported at NIH.

#### NIGMS SHOULD SUPPORT BASIC BEHAVIORAL SCIENCE RESEARCH

The situation at NIMH underscores the need for a dependable "home" for basic behavioral science research and training at NIH. In fact, that is the recommendation of the NIH Director's own Working Group on Research Opportunities in the Basic Behavioral and Social Sciences, which also recommended the National Institute of General Medical Sciences (NIGMS), known as NIH's "basic research institute." Congress has given NIGMS a statutory mandate [TITLE 42, CHAPTER 6A, SUBCHAPTER III, Part C, subpart 11, Sec. 285k] to support basic behavioral research and training, but that mandate has not been fulfilled.

As early as fiscal year 2000, this committee, along with your colleagues in the House, has repeatedly issued report language urging NIGMS to fund basic behavioral research and training, saying, for example: "There is a range of basic behavioral research and training that the institute could support, such as the fundamental relationships between the brain and behavior, basic cognitive processes such as motivation, learning, and information processing, and the connections between mental processes and health. The committee encourages NIGMS to support basic behavioral research and training and to consult with the behavioral science research community and other Institutes to identify priority research and training areas." [House Fiscal Year 2000 Appropriations Report 106-370]

As a result of meetings between NIH Deputy Director Raynard Kington and Representatives Kennedy and Baird, the NIH Director commissioned a panel of outside experts in 2004 to study the matter. This Working Group, which was convened under the auspices of the NIH Director's Advisory Council, spent a year assessing the state of basic behavioral research throughout NIH. In its final report to NIH, the Working Group formally recommended the establishment of a secure and stable home for basic behavioral science research and training at NIH. In particular, it suggested that an Institute such as NIGMS should be that home, as this committee, the Institute of Medicine, and the National Academy of Sciences have recommended. NIH has deflected this request, made by multiple entities, time and time again. In view of the fact that 8 of the 10 leading causes of death have a significant behavioral component and that basic research is the underpinning of advances in applied behavioral research, the continued lack of focus of scientific leadership at NIH for this important field of science is counter to the interests of the Nation's health needs.

Basic behavioral research in the cognitive, psychological, and social processes underlying substance abuse and addiction (significance for NIDA, NIAAA, NCI and NHLBI), obesity (significance for NIDDK, NHLBI, and NICHD) and the connections between the brain and behavior (significance for NIMH, NINDS, and NHGRI) just to name a few, all are within the NIGMS mission. Greater involvement between the behavioral science community and NIGMS is an alliance that can reap enormous benefits for NIGMS, for behavioral science, for medical science, and for the public welfare. It is our feeling that the time is ripe for NIGMS to provide a supportive home for the kinds of basic behavioral science research that will be critical to fulfilling the NIGMS mission in the coming years. Given the statutory mandate, the recommendations of a recent Director's advisory council's task force, the strong congressional interest, the recommendations of the National Academy of Sciences and the Institute of Medicine, the scientific imperative, and most important, the health needs of the Nation, APS asks the committee to request the Office of the Director to submit to the committee a report indicating the structure for scientific leadership for this important field within the appropriate grant making institute, by November 16, 2007.

#### BEHAVIORAL SCIENCE AT KEY INSTITUTES

In the remainder of this testimony, we highlight examples of cutting-edge behavioral science research being supported by individual institutes.

*National Institute of Mental Health (NIMH).*—In addition to our earlier discussion of NIMH, we would like to give special recognition to the Institute's support of the emerging field of Social Neuroscience, which investigates the interaction of biological mechanisms and social processes and behavior. We commend NIMH for making this a priority. Elucidating the complex interplay between brain and social behavior will help us better understand and treat mental disorders such as autism and schiz-

ophrenia, and will lead to cognitive therapies for treating the emotion dysregulation associated with post-traumatic stress, depression, and cardiovascular disease.

*National Institute on Drug Abuse (NIDA).*—By supporting a comprehensive research portfolio that stretches across basic neuroscience, behavior, and genetics, NIDA is leading the Nation to a better understanding and treatment of drug abuse. Risky Decision-Making and HIV/AIDS—NIDA-funded research is examining every aspect of the transmission of HIV/AIDS through drug abuse and addiction, including risk-taking behaviors associated with both injection and non-injection drug abuse, how drugs of abuse alter brain function and impair decision making, and HIV prevention and treatment strategies for diverse groups. The goal is to achieve a broad understanding of the multiple ways that drug abuse and addiction affect HIV/AIDS and how research can inform public health policy. APS asks this committee to support this and other critical behavioral science research at NIDA, and to increase NIDA's budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

It's not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those reviewed in this statement, many other institutes play a key role in NIH behavioral science research enterprise. These include the National Institute on Alcohol Abuse and Alcoholism, the National Cancer Institute, the National Institute for Child Health and Human Development, the National Institute on Aging, the National Heart, Lung, and Blood Institute, and the National Institute of Diabetes and Digestive and Kidney Diseases. Behavioral science is a central part of the mission of these institutes, and their behavioral science programs deserve the committee's strongest possible support.

This concludes our testimony. Again, thank you for the opportunity to discuss NIH appropriations for fiscal year 2008 and specifically, the importance of behavioral science research in addressing the Nation's public health concerns. We would be pleased to answer any questions.

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PREPARED STATEMENT OF THE ASSOCIATION FOR RESEARCH IN VISION AND  
OPHTHALMOLOGY (ARVO)

EXECUTIVE SUMMARY

ARVO requests fiscal year 2008 NIH funding at \$31 billion, or a 6.7 percent increase over fiscal year 2007, to balance the biomedical inflation rate of 3.7 percent and to maintain the momentum of discovery. Although ARVO commends the leadership's actions in the 110th Congress to increase fiscal year 2007 NIH funding by \$620 million, this was just an initial step in restoring the NIH's purchasing power, which has declined by more than 13 percent since the budget doubling ended in fiscal year 2003. That power would be eroded even further under the President's proposed fiscal year 2008 budget. ARVO commends NIH Director Dr. Zerhouni, who has articulately described his agenda to foster collaborative, cost-effective research and to transform the healthcare research and delivery paradigm into one that is predictive, preemptive, preventive, and personalized. NIH is the world's premier institution and must be adequately funded so that its research can reduce healthcare costs, increase productivity, improve quality of life, and ensure our Nation's global competitiveness.

ARVO requests that Congress make vision health a top priority by funding the NEI at \$711 million in fiscal year 2008, or a 6.7 percent increase over fiscal year 2007. This level is necessary to fully advance the breakthroughs resulting from NEI's basic and clinical research that are resulting in treatments and therapies to prevent eye disease and restore vision. Vision impairment/eye disease is a major public health problem that is growing and which disproportionately affects aging and minority populations, costing the United States \$68 billion annually in direct/societal costs, reduced independence, and quality of life. NEI funding is a cost-effective investment in our Nation's health, as it can delay and prevent expenditures, especially to the Medicare and Medicaid programs.

Adequate NEI funding is also essential to a strong and vibrant research community, which risks losing established investigators. The flat funding in recent years may cause young investigators to pursue other careers and thus fail to keep the research pipeline strong. ARVO is especially concerned about the impact on clinician scientists who have been so instrumental to the NEI's successful track record of the translations of basic research into clinical applications that directly benefit the American people.

## ABOUT ARVO

ARVO is the world's largest association of physicians and scientists who study diseases and disorders affecting vision and the eye. ARVO has more than 11,700 members from the United States and 70 countries, and some 80 percent of U.S. members have grants from the National Eye Institute. It is in that regard that ARVO submits these comments in support of increased fiscal year 2008 NIH and NEI funding.

FUNDING THE NEI AT \$711 MILLION IN FISCAL YEAR 2008 ENABLES IT TO LEAD TRANS-INSTITUTE VISION RESEARCH THAT MEETS NIH'S GOAL OF PREEMPTIVE, PREDICTIVE, PREVENTIVE, AND PERSONALIZED HEALTHCARE

Funding NEI at \$711 million in fiscal year 2008 represents the eye and vision research community's judgment as that necessary to fully advance breakthroughs resulting from NEI's basic and clinical research that are resulting in treatments and therapies to prevent eye disease and restore vision.

NEI research responds to the NIH's overall major health challenges, as set forth by Dr. Zerhouni: an aging population; health disparities; the shift from acute to chronic diseases; and the co-morbid conditions associated with chronic diseases (e.g., diabetic retinopathy). In describing the predictive, preemptive, preventive, and personalized approach to healthcare research, Dr. Zerhouni has frequently cited NEI-funded research as tangible examples of the value of our Nation's past and future investment in the NIH. These include:

- Dr. Zerhouni has cited as a breakthrough the collaborative Human Genome Project/NEI-funded discovery of gene variants strongly associated with an individual's risk of developing age-related macular degeneration (AMD), the leading cause of blindness (affecting more than 10 million Americans) which increasingly robs seniors of their independence and quality of life. These variants, which are responsible for about 60 percent of the cases of AMD, are associated with the body's inflammatory response and may relate to other inflammation-associated diseases, such as Alzheimer's and Parkinson's disease. As NEI Director Dr. Paul Sieving has stated, "One of the important stories during the next decade will be how Alzheimer's disease and macular degeneration fit together."
- Dr. Zerhouni has cited the NEI-funded Age-Related Eye Disease Study (AREDS) as a cost-effective preventive measure. In 2006, NEI began the second phase of the AREDS study, which will follow up on initial study findings that high levels of dietary zinc and antioxidant vitamins (Vitamins C, E and beta-carotene) are effective in reducing vision loss in people at high risk for developing advanced AMD—by a magnitude of 25 percent.
- NEI has funded research, along with the National Cancer Institute (NCI) and the National Heart, Lung, and Blood Institute (NHLBI), into factors that promote new blood vessel growth (such as Vascular Endothelial Growth Factor, or VEGF). This has resulted in anti-VEGF factors that have been translated into the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing vision loss. Current research is focused on using treatments singly and in combination to improve vision or prevent further vision loss due to AMD. As part of its Diabetic Retinopathy Clinical Research Network, NEI is also evaluating these drugs for treatment of macular edema associated with diabetic retinopathy.

Although these breakthroughs came directly from the past doubling of the NIH budget, their long-term potential to preempt, predict, prevent, and treat disease relies on adequately funding NEI's follow-up research. Unless its funding is increased, the NEI's ability to capitalize on the findings cited above will be seriously jeopardized, resulting in "missed opportunities" that could include:

- Following up on the AMD gene discovery by developing diagnostics for early detection and promising therapies, as well as to further study the impact of the body's inflammatory response on other degenerative eye diseases.
- Fully investigating the impact of additional, cost-effective dietary supplements in the AREDS study, singly and in combination, to determine if they can demonstrate enhanced protective effects against progression to advanced AMD.
- Following up with further clinical trials on patients with the "wet" form of AMD, as well as patients with diabetic retinopathy, using the new anti-angiogenic ophthalmic drugs singly and in combination to halt disease progression and potentially restore vision.

In addition, NEI research into other significant eye disease programs, such as glaucoma and cataract, will be threatened, along with quality of life research programs into low vision and chronic dry eye. This comes at a time when the U.S. Census and NEI-funded epidemiological research (also threatened without adequate

funding) both cite significant demographic trends that will increase the public health problem of vision impairment and eye disease.

Adequate NEI funding is also essential to a strong and vibrant research community, which risks losing established investigators. The flat funding in recent years may cause young investigators to pursue other careers and thus fail to keep the research pipeline strong. ARVO is especially concerned about the impact on clinician scientists who have been so instrumental to the NEI's successful track record of the translations of basic research into clinical applications that directly benefit the American people.

VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT IS INCREASING HEALTHCARE COSTS, REDUCING PRODUCTIVITY, AND DIMINISHING QUALITY OF LIFE

The 2000 U.S. Census reported that more than 119 million people in the United States were age 40 or older, which is the population most at risk for an age-related eye disease. The NEI estimates that, currently, more than 38 million Americans age 40 and older experience blindness, low vision or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of other chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the United States is \$68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to both the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As a result, Federal funding for the NEI is a vital investment in the health, and vision health, of our Nation, especially our seniors, as the treatments and therapies emerging from research can preserve and restore vision. Adequately funding the NEI can delay and prevent expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

ARVO urges fiscal year 2008 NIH and NEI funding at \$31 billion and \$711 million, respectively.

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PREPARED STATEMENT OF THE ASSOCIATION OF WOMEN'S HEALTH, OBSTETRIC AND NEONATAL NURSES

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) appreciates the opportunity to provide comments on the fiscal year 2008 appropriations for nursing education, research, and workforce development programs as well as programs designed to improve maternal and child health. AWHONN is a membership organization of 22,000 nurses, and our mission is to promote the health and well-being of all women and newborns. AWHONN members are registered nurses, nurse practitioners, certified nurse-midwives, and clinical nurse specialists who work in hospitals and health systems, physicians' practices, universities, and community clinics throughout the United States.

DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

*AWHONN recommends \$1 million in fiscal year 2008 funding to convene a Surgeon General's conference on preterm birth*

Premature birth is the leading cause of neonatal death. Each year, an estimated 1 in 8 births is premature. A 2006 report by the Institute of Medicine found that the annual economic burden associated with preterm birth is at least \$26.2 billion. This translates to \$51,600 per preterm infant. The PREEMIE Act (Public Law 109-450) authorized funding to convene a Surgeon General's conference to establish a public-private research and education agenda to accelerate the development of new strategies for preventing preterm birth. This Surgeon General's conference is a critical step in reducing this growing challenge.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

*AWHONN recommends a minimum of \$7.5 billion in funding for HRSA*

AWHONN is deeply concerned by the President's budget request, which eliminates 12 programs and cuts over \$200 million from the Federal funds HRSA received in 2007. Through its many programs and new initiatives, HRSA provides for the Nation's most vulnerable citizens. Rapid advances in research and technology promise unparalleled change in the Nation's health care delivery system. In order to take reasonable advantage of these opportunities, HRSA will require an overall funding level of at least \$7.5 billion for fiscal year 2008.

## TITLE VIII—NURSING WORKFORCE DEVELOPMENT PROGRAMS UNDER HRSA

*AWHONN recommends a minimum of \$200 million in funding for Title VIII*

Nursing workforce development programs authorized under Title VIII of the Public Health Service Act, are an essential component of the American health care safety net. Title VIII programs are the only comprehensive Federal programs that provide annual funds for nursing education. These funds help nursing schools and students prepare to meet changing patient needs and provide clinical education to promote practice in medically underserved communities and Health Professional Shortage Areas.

The President's budget recommends a 30 percent reduction in funding at \$105 million for fiscal year 2008, despite the worsening nursing shortage. AWHONN believes a minimum of \$200 million is needed to adequately fund in funding for Title VIII Nursing Workforce Development. In addition, AWHONN supports funding the Advanced Education Nursing Training Program (sec. 811) at an increased level on par with other Title VIII programs in fiscal year 2008.

In 2002, Congress enacted the Nurse Reinvestment Act, which provides funding for programs such as the Nurse Education Loan Repayment Program (NELRP), internships and residencies, retention programs, and faculty loans designed to encourage students to consider nursing, retain nurses, and increase nurse educators. These new programs received an initial appropriation of \$20 million in fiscal year 2003, in addition to \$93 million provided for existing Title VIII programming. Inadequate funding stunted the potential of loan and scholarship programs and limited the support to nursing students. For example, NELRP is a competitive program that repays 60 percent of the qualifying loan balance of registered nurses selected for funding in exchange for 2 years of service at a critical shortage facility. In fiscal year 2005, the NELRP received 4,465 applications and dispersed 803 awards; an 18 percent award rate. In fiscal year 2006, NELRP assessed 4,222 applications and gave 615 awards; only a 14 percent award rate. The award trend is going in the wrong direction.

*Increased Funding for Title VIII Will Make a Positive Impact on the Nursing Shortage.*—Recent data from the Bureau of Health Professions, Division of Nursing's The Registered Nurse Population: National Sample Survey of Registered Nurses, Preliminary Findings—March 2007, confirm that of the approximately 2.9 million registered nurses in the Nation only 83 percent of these nurses work full-time or part-time in nursing. A dominant factor in this shortage is the impending retirement of up to 40 percent of the workforce by 2010. The average age of a nurse according to a 2004 sample survey is 46.8 compared to 45.2 in the 2000 survey. This anticipated wave of retirement will occur as the needs of the aging baby boomer population will markedly increase demand for health care services and registered nurses. Also, the 2007 U.S. Bureau of Labor and Statistics report projected that registered nurses will have the largest 10-year job growth; about 1 million new job openings by 2010.

The shortage of registered nurses and its effect on staffing levels, patient safety, and quality care demands attention and a significant increase in funding to bolster and improve these programs. Nursing is the largest health profession, yet only .2 percent of Federal health funding is devoted to nursing education. A significant increase in funding for these programs can help lay the groundwork for expanding the nursing workforce, through education, clinical training and retention programs.

*Increased Funding for Title VIII Will Help Fill the Nursing Faculty Gap.*—AWHONN supports efforts to recruit new faculty and increase nursing faculty available to teach in nursing schools. Currently, according to the National League for Nursing, there are fewer than 17,000 full-time faculty members. The estimated number of nurse faculty required to meet current demand is estimated to be 40,000 nurse educators. The Advanced Nurse Education funding in fiscal year 2005 produced 11,949 graduate nursing students, who are the primary pool for future faculty.

Nursing faculty continues to decrease in number as nursing school applications have surged more than 59 percent over the past decade. In a NLN survey of the 2004–2005 academic year, nursing programs at all degree levels turned away an estimated 147,000 qualified applications because of the lack of faculty. This number represents a 17.6 percent increase from last year's figures. Without sufficient support for current nursing faculty and adequate incentives to attract future faculty, nursing schools will fail to have the teaching infrastructure necessary to educate and train our next generation of nurses.

While the capacity to implement faculty development is currently available through section 811 and section 831, adequate funding and direction is needed to ensure that these programs are fully operational. Options to provide support for full-time doctoral study are essential to rapidly prepare future nurse educators. AWHONN recommends that a portion of the funds be allocated for faculty development and mentoring.

*Funding Advanced Practice Nurses Provides Needed Faculty and Primary Care Providers.*—Advanced Practice nurses such as nurse practitioners, clinical nurse specialists, certified registered nurse anesthetists and certified nurse midwives are essential to eliminating the nursing shortage. As in other professions, the advanced degree has become a necessary achievement for career advancement. Registered nurses who pursue MSN and PhD degrees often go on to become faculty and essential health care providers. The nursing shortage encompasses both advanced practice and basic nursing; each must receive additional funding but not at the expense of one another. In addition, advanced practice nurses are critical and sometimes the only available primary care providers, and often serve in inner city, rural and frontier health care settings.

The entire nursing workforce needs strengthening. As a result, it will take long-term planning and innovative initiatives at the local, State and Federal levels to ensure an adequate supply of a qualified nurse workforce for the Nation. Federal investment in nursing education and retention programs is critical for meeting the health care needs of our Nation.

#### TITLE V—MATERNAL AND CHILD HEALTH BUREAU (MCHB) UNDER HRSA

##### *AWHONN recommends \$731 million in funding for MCHB*

The Maternal and Child Health Bureau incorporates valuable programs like the Traumatic Brain Injury program, Universal Newborn Hearing Screening, Emergency Medical Services for Children, and Healthy Start, which were zeroed out, and the Maternal and Child Health Block Grant (MCH) that saw no funding growth from the previous year. These programs provide comprehensive, preventive care for mothers and young children, and an array of coordinated services for children with special needs. In fact, MCH serves over 80 percent of all infants, half of all pregnant women and 20 percent of all children in the United States.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

##### *AWHONN recommends a 6.7 percent increase in appropriation funding for NIH*

Multiple institutes housed under the National Institutes of Health (NIH) serve valuable roles in helping promote the importance of nursing in the health care industry along with the health and well-being of women and newborns. AWHONN calls on Congress to implement a 6.7 percent increase in funding for NIH in each of the next 3 years. This funding will allow scientists, including nurse scientists, to continue making life-saving research breakthroughs and discoveries. This funding also is the estimated amount needed to sustain the current model of NIH research funding.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR) UNDER NIH

##### *AWHONN recommends \$150 million in funding for NINR*

The National Institute of Nursing Research (NINR) engages in significant research affecting areas such as health disparities among ethnic groups, training opportunities for management of patient care and recovery, and telehealth interventions in rural/underserved populations. This research allows nurses to refine their practice and provide quality patient care. For example, NINR research is invaluable in contributing to improved health outcomes for women. Recent public awareness campaigns target differences in the manifestation of cardiovascular disease between men and women. The differing symptoms are the source of many missed diagnostic opportunities among women suffering from the disease, which is the primary killer of American women. Because of the emphasis on biomedical research in this country, there are few sources of funds for high-quality behavioral research for nursing

other than NINR. It is critical that we increase funding in this area in an effort to optimize patient outcomes and decrease the need for extended hospitalization. While the President's budget recommended a decrease at \$138 million, AWHONN requests \$150 million for fiscal year 2008, consistent with the overall increase for all National Institutes of Health.

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD) UNDER NIH  
*AWHONN recommends \$1.34 billion in funding for NICHD*

The National Institute of Child Health and Human Development (NICHD) seeks to ensure that every baby is born healthy, that women suffer no adverse consequences from pregnancy, and that all children have the opportunity for a healthy and productive life unhampered by disease or disability. For example, with increased funding, NICHD could expand its use of the NICHD Maternal-Fetal Medicine Network to study ways to reduce the incidence of low birth weight. Prematurity/low birth weight is the second leading cause of infant mortality and the leading cause of death among African American infants. AWHONN is directly involved in programs to improve the health of women and newborns and looks to NICHD to provide national initiatives that assist with the care of pregnant women and babies. AWHONN suggests a 6.7 percent increase in NICHD funding to \$1.34 billion.

NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS) UNDER NIH  
*AWHONN recommends \$673 million for NIEHS*

Research conducted by NIEHS plays a critical role in what we know about the relationship between environmental exposures and the onset of diseases. Through their research, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases have confirmed environmental triggers. Our expanded knowledge, allows policymakers and the public to make important decisions about how to reduce toxin exposure, the risk of disease and other negative health outcomes. As the prevalence of infertility and related reproductive challenges continues to increase according to the CDC, the investment in improving our understanding of environmental impacts should be increased to \$673 million.

INDIAN HEALTH SERVICE (IHS) UNDER THE DEPARTMENT OF HEALTH AND HUMANS  
 SERVICES (HHS)

*AWHONN recommends \$3.5 billion in funding for IHS*

The Indian Health Service (IHS) is the principal Federal health care provider and health advocate for the American Indian and Alaska Native populations. The President's budget recognizes this importance by requesting a 6.9 percent increase of \$211 million to the IHS budget, bringing the fiscal year 2008 total to \$3.27 billion. While AWHONN applauds this increase, we recommend that a total of \$3.5 billion is needed for IHS to fully achieve its legitimate goals. A recent study of Federal health care spending per capita found that the United States spends \$5,065 per year for the general population, \$3,803 per year for a Federal prisoner, and only \$1,914 for a Native American. Where health needs continue at unprecedented levels and the average age of nurses (48) is higher than for the general public. The nursing shortage has disproportionately affected Indian Health Services. Further, the average reported vacancy rate for RNs in 2006 was 18 percent. IHS administers three severely under-funded interrelated scholarship programs designed to meet the health professional staffing needs of IHS and other health programs serving Indian people. Targeted resources need to be invested in the IHS health professions programs to recruit and retain registered nurses.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) UNDER HHS

*AWHONN recommends \$52 million for Safe Motherhood/Infant Health to fund activities authorized by the PREEMIE Act*

This would include epidemiological studies on preterm birth, including the relationship between prematurity, birth defects and developmental disabilities.

AWHONN thanks you for your consideration and greatly appreciates this opportunity to submit testimony on these critical funding areas.

## PREPARED STATEMENT OF THE AUTISM SOCIETY OF AMERICA

My name is Ruth Elaine Hane. I live in Minneapolis, Minnesota, where I facilitate a social group, the Aspie Get-Together, for adults with Aspergers and autism. It is a privilege to testifying on behalf of my self and other adults on the spectrum of autism. I appreciate sharing my story with strong advocates for autism, Senators Harkin, Specter and Durbin. Thank you, for all you do, to improve the lives of those affected by autism.

Several others have given testimony to this subcommittee, emphasizing the needs of children with autism who are waiting for essential services, and I do not deny that this is a critical issue, but, there are others who are also waiting, adults who have aged out of the system after 21, and are now left without support. A portion of these adults benefited from the various programs for early intervention in the past two decades, but are lacking employment and life skills to live independently. Many are sitting at home in front of their parent's computer or television screen without the quality of life they were promised.

I was born with autism, sometimes referred to as a "Rubella baby," since my mother had a severe case of Rubella Measles during her pregnancy with me. A delivery using forceps injured and distorted my head. I screamed for continuously, could not swallow or tolerate touch. My mother was advised by her doctor, not to become attached to her baby girl, because there was little hope of my survival, and, even if I did, I would never be normal. But, I did live, because of a community of neighbors who problem solved, volunteered, and taught my mother how to care for me. The bases of their practical advice came from sheep ranching, and the methods they used to nurture baby lambs who were born with neurological problems like mine . . . to wrap me tightly in a warm blanket, place me in a box set on the slightly warmed oven door and to drip goat's milk into my mouth. Since the sound of ticking clock calmed me, it was placed near the box. I was not to be clothed, or disturbed for 3 hours at a time. Over time, I began to grow, however I did not acclimate to touch, or learn to coo, or respond to others.

I identified with cats and not people, and did not talk until I was 4 years old. The small town where we lived accepted me as an "unusual" child who was stubborn, independent, and overly active, skipping, twirling, and singing to herself. Autism was not well-known by the doctors at that time. My grandmother, who was a school teacher, stepped in to give me love, taught me manners and structured learning. I graduated with honors from college, married and had two children, who are now grown. My second husband and I are grandparents. Presently, I volunteer in the community and serve as First vice Chair on the national board, of the Autism Society of America. I consult with sensitive people, many of whom are on the spectrum of autism.

My message is that most adults with autism are greatly underserved. Autism is sometimes called hidden, because many people like me look normal. Some, have learned to accommodate, to pretend to be normal, but, others have odd social communication and behaviors especially when there are stressful situations, such as loud noise, flashing emergency lights, florescent lighting, confusing verbal directions and poor signs in public places. Since our brains are unable to processes the incoming information in a timely way, we are put a risk socially, sometimes hurt, bullied, raped or even killed. Depression is common with little hope of living a productive independent life, even though many are educated, with college degrees, and some with graduate and doctoral degrees.

After I was diagnosed, as an adult, with High Functioning autism, I became active in the local Autism Society of America, Minnesota State Chapter. In 1999, several young adults on the spectrum asked if I would organize and facilitate a group for people diagnosed with Aspergers and autism. They wanted a place to socialize and meet friends. I formed the Aspie Get-Together.

The Aspie Get-Together is an all voluntary group of mostly young adults, run and governed by the participants. Since most of our members are unemployed or under employed, the nominal membership dues are often waived. We are limited in the activities that we can do because of this lack of funding. However it is a demonstration of how people who are often marginalized and at times, ostracized, because of a difference in social skills, can become, productive members of a group, and, of society at large if given structure, guidance and the opportunity to be themselves.

Those with autism, who are living with their parents, are under a cloud of uncertainty with parents who are aging, anguishing about the future of their dependent adult with autism. With our population shifting toward a nuclear family unit, we can no longer depend on the extended family to fill in this gap. We need appropriations to fund services to change this grave situation in America. With applied research, job and life skills training, community building and mentors, who could pro-

vide several hours of weekly planning and guidance, so that the underserved people with autism could work, lead productive lives and contribute to society in unique and beneficial ways. In addition, there are those who are profoundly affected by autism, who need 24 hours a day of assistance and supervision. The best and most successful programs today, are based on empowering the individual to make personal choices, allowing for, as much independence as is possible. Without exception, these providers are under funded.

Although those of us with autism diagnoses are directly affected by choices others make about and for us, our voice is seldom heard.

I dream of a society that embraces difference of all kinds, including autism, and a society that listens to those with autism—who can speak.

Please remember to include us so that there is . . . Nothing about us . . . without us.

Thank you.

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PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION  
COALITION

The CDC Coalition is a nonpartisan coalition of more than 100 groups committed to strengthening our Nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in Federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective State and local programs. Coalition member groups represent millions of public health workers, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency—not just the individual programs that it funds. In the best judgment of the CDC Coalition—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least \$10.7 billion including sufficient funding to prepare the Nation against a potential influenza pandemic, funding for the Agency for Toxic Substances and Disease Registry and to maintain the current funding level for the Vaccines for Children (VFC) program. This request does not include any additional funding that may be required to expand the mandatory VFC in fiscal year 2008.

The CDC Coalition appreciates the subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, and environmental health programs at CDC. Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our Nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

CDC's budget has actually shrunk since 2005 in terms of real dollars—by almost 4 percent. If you add inflation, the cuts are even worse—and these are cuts to the core programs of the agency. The current administration request for fiscal year 2008 is inadequate, with a total cut to core budget categories from fiscal year 2005 to fiscal year 2008 of half a billion dollars. We are moving in the wrong direction, especially in these challenging times when public health is being asked to do more, not less. It simply does not make any sense to cut the budget for CDC core public health programs at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

CDC serves as the lead agency for bioterrorism preparedness and must receive sustained support for its preparedness programs in order for our Nation to meet future challenges. In the best judgment of CDC Coalition members, given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities, we support the proposed increase for

anti-terrorism activities at CDC, including the increases for the Strategic National Stockpile. However, we strongly oppose the President's proposed \$125 million cut to the State and local capacity grants. We ask the subcommittee to restore these cuts to ensure that our States and local communities can be prepared in the event of an act of terrorism or other public health threat.

Public health programs delivered at the State and local level should be flexible to respond to State and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for States and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. However, the President's budget once again proposes the elimination of the PHHS Block Grant. We greatly appreciate the work of the subcommittee to at least partially restore the fiscal year 2007 elimination of the Block Grant. Nevertheless, the cut to the Block Grant in fiscal year 2006 reduces the States' ability to tailor Federal public health dollars to their specific needs.

#### ADDRESSING URGENT REALITIES

Heart disease remains the Nation's No. 1 killer. In 2004, more than 650,000 people died from heart disease, accounting for 27 percent of all U.S. deaths. In 1998, the U.S. Congress provided funding for CDC to initiate a national, state-based Heart Disease and Stroke Prevention Program with funding for eight States. Now, 32 States and the District of Columbia are funded, 19 as capacity building and 14 as basic implementation. We must expand these efforts to continue the gains we have made in combating heart disease and stroke.

The CDC funds proven programs addressing cancer prevention, early detection, and care. In 2006, about 1.4 million new cases of cancer will be diagnosed, and about 564,830 Americans—more than 1,500 people a day—are expected to die of the disease. The financial cost of cancer is also significant. According to the National Institutes of Health, in 2005, the overall cost for cancer in the United States was nearly \$210 billion: \$74 billion for direct medical costs, \$17.5 billion for lost worker productivity due to illness, and \$118.4 billion for lost worker productivity due to premature death.

Among the ways the CDC is fighting cancer, is through funding the National Breast and Cervical Cancer Early Detection Program that helps low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds programs to raise awareness about colorectal, prostate, lung, ovarian and skin cancers, and the National Program of Cancer Registries, a critical registry for tracking cancer trends in all 50 States.

Although more than 20 million Americans have diabetes, 6.2 million cases are undiagnosed. From 1980–2002, the number of people with diabetes in the United States more than doubled, from 5.8 million to 13.3 million. Unfortunately funding for diabetes, along with many other core CDC programs, has either been cut or flat funded for the past several years. Without additional funds, most States will not be able to create programs based on these new data. States also will continue to need CDC funding for diabetes control programs that seek to reduce the complications associated with diabetes.

Over the last 25 years, obesity rates have doubled among adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The CDC funds programs to encourage the consumption of fruits and vegetables, to get sufficient exercise, and to develop other habits of healthy nutrition and activity. In order to fully support these activities, we urge the subcommittee to provide at least \$43 million for the Steps to a Healthier U.S. program and \$65 million for CDC's Division of Nutrition and Physical Activity.

Childhood immunizations provide one of the best returns on investment of any public health program. Despite the incredible success of the program, it faces serious financial challenges. In the past 10 years, the number of recommended childhood vaccines has jumped from 10 to 16. Even more striking, the cost of fully vaccinating an adolescent female has increased from \$285 to over \$1,200 in past 8 years alone. Despite these challenges funding for vaccine purchases under section 317 has remained stagnant. The consequence of this disconnect, is that while 747,000 children and adolescents could potentially receive their full series of vaccinations with 317 funds in 1999, that number has plummeted by over 70 percent to just 218,000 in 2007.

More than 400,000 people die prematurely every year due to tobacco use. CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

Almost 80 percent of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30 percent of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and about 3 million become infected with a sexually transmitted disease. School health programs are one of the most efficient means of correcting these problems, shaping our Nation's future health, education, and social well-being.

Much of CDC's work in chronic disease prevention and health promotion is guided by its prevention research activities. Healthy Passages is a longitudinal study that is following a cohort of children who will have to be discontinued without \$6 million in additional appropriations. If allowed to continue, the study would follow children from birth through adulthood in order to discover critical links between risks and protective factors and health outcomes.

CDC provides national leadership in helping control the HIV epidemic by working with community, State, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that up to 1,185,000 Americans are living with HIV, one-quarter of who are unaware of their infection. Prevention of HIV transmission is our best defense against the AIDS epidemic that has already killed over 500,000 U.S. citizens and is devastating the populations of nations around the globe, and CDC's HIV prevention efforts must be expanded.

The United States has the highest sexually transmitted diseases (STD) rates in the industrialized world. More than 18 million people contract STDs each year. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. State and local STD control programs depend heavily on CDC funding for their operational support.

CDC conducts several surveys that help track health risks and provide information for priority setting at the State and local levels. The Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, and National Health and Nutrition Examination Survey (NHANES) are important national sources of objective health data. NHANES is a unique collaboration between CDC, the National Institutes of Health (NIH), and others to obtain data for biomedical research, public health, tracking of health indicators, and policy development. Ensuring adequate funding for this survey is essential for determining rates of major diseases and health conditions and developing public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), helps States address these serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. We encourage the subcommittee to provide adequate funds for CDC's REACH program.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save health care costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination and significant racial and ethnic disparities in vaccination levels persist among the elderly.

Injuries are the leading cause of death in the United States for people ages 1–34. Of all injuries, those to the brain are most likely to result in death or permanent disability. Traumatic brain injury (TBI) is widely recognized as the signature wound of the Iraq war with estimates of the numbers of injured service members as high as 150,000. Each year, however, more than 50,000 civilians die and 90,000 civilians are left with a long-term disability as a result of TBI. The Traumatic Brain Injury Act is the Nation's only law that specifically responds to this growing public health crisis. The Institute of Medicine found that this law has been effective in addressing a wide variety of gaps in service system development.

Injury at work remains a leading cause of death and disability among U.S. workers. During the period from 1980 through 1995, at least 93,338 workers in the United States died as a result of injuries suffered on the job, for an average of about 16 deaths per day. The injury prevention and workforce protection initiatives of NIOSH need continued support.

Created by the Children's Health Act of 2000 (Public Law 106–310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC con-

ducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities. We must ensure adequate funding for this important Center.

We also encourage the subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, State and local. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, *E. coli* and lead in drinking water. We encourage the committee to provide at least \$50 million for CDC's Environmental Health Tracking Network and to provide \$50 million in new funding to CDC Environmental Health Activities to develop and enhance CDC's capacity to help the Nation prepare for and adapt to the potential health effects of global climate change. This new request for funding would help prepare State and local health department to prepare for the public health impacts of global climate change, allow CDC to fund academic and other institutions in their efforts to research the impacts of climate change on public health and to create a Center of Excellence at CDC to serve as a national resource for health professionals, government leaders and the public on climate change science.

We appreciate the subcommittee's hard work in advocating for CDC programs in a climate of competing priorities. We encourage you to consider our request for \$10.7 billion, plus sufficient funding to prepare for a possible influenza pandemic, for CDC in fiscal year 2008.

#### MEMBERS OF THE CDC COALITION

Advocates for Youth; AIDS Action; AIDS Alliance for Children, Youth and Families; AIDS Foundation Chicago; Alliance to End Childhood Lead Poisoning; American Academy of Ophthalmology; American Academy of Pediatrics; American Association for Health Education; American Association of Orthopedic Surgeons; American Cancer Society; American College of Obstetricians and Gynecologists; American College of Preventive Medicine; American College of Rheumatology; American Dietetic Association; American Foundation for AIDS Research; American Heart Association; American Indian Higher Education Consortium; American Lung Association; American Medical Women's Association; American Optometric Association; American Podiatric Medical Association; American Psychological Association; American Psychological Society; American Public Health Association; American Red Cross; American School Health Association; American Society for Clinical Pathology; American Society for Gastrointestinal Endoscopy; American Society for Microbiology; American Society for Reproductive Health; American Thoracic Society; American Urological Association c/o MARC Assoc.; Arthritis Foundation; Assn. for Professionals in Infection Control & Epidemiology; Association of American Medical Colleges; Association of Maternal & Child Health Programs; Association of Minority Health Professions Schools; Association of Public Health Laboratories; Association of Reproductive Health Professionals; Association of Schools of Public Health; Association of State and Territorial Health Officials; Association of Teachers of Preventive Medicine; Barbara Levine & Associates; Brain Injury Association; Bread for the World Institute; Campaign for Tobacco-Free Kids; CDC Foundation; Center for Science in the Public Interest; Coalition for Health Funding; Coalition for Health Services Research; Commissioned Officers Association of the U.S. Public Health Service; Consortium for Citizens with Disabilities; Consortium of Social Science Associations; Council of Professional Association on Federal Statistics; Council of State and Territorial Epidemiologists; Crohn's and Colitis Foundation of America; Environmental Defense; ESA, Inc.; Every Child By Two; GLMA; Health and Medicine Counsel of Washington; Hepatitis Foundation International; Immune Deficiency Foundation; Infectious Diseases Society of America; Latino Council on Alcohol & Tobacco; Legal Action Center; March of Dimes; NASEMSD; National Alliance of State and Territorial AIDS Directors; National Association of Children's Hospitals; National Association of County and City Health Officials; National Association of Councils on Developmental Disabilities; National Association of Local Boards of Health; National Association of School Nurses; National Black Nurses Association; National Coalition for the Homeless; National Coalition of STD Directors; National Council of La Raza; National Episcopal AIDS Coalition; National Family Planning and Reproductive Health Association; National Health Care for the Homeless Council; National Hemophilia Foundation c/o MARC Assoc.; National Medical Association; National Osteoporosis Foundation; National Partnership for Immunization; National Rural Health Association; National Safe Kids Campaign; National Association for Public Health Statistics & Information Systems & Information Systems; Partner-

ship for Prevention; Planned Parenthood Federation of America; Powers, Pyles, Sutter and Verville; Research!America; Society for Maternal Fetal-Medicine c/o CRD Associates; Society for Public Health Education; Society of General Internal Medicine (SGIM); Spina Bifida Association of America; The Alan Guttmacher Institute; Trust for America's Health; U.S. Conference of Mayors; United Cerebral Palsy; YMCA of the USA; and YWCA of the USA/Office of Women's Health Initiative.

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PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND  
SCIENCE

SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

\$300 million for the Health Resources and Services Administration Title VII Health Professions Training programs, including:

- \$33.6 million for the Minority Centers of Excellence, and
- \$35.6 million for the Health Careers Opportunity program.

Provide a 6.7 percent increase for fiscal year 2008 to the National Institutes of Health (NIH), specifically:

- A proportional increase to the National Cancer Institute (NCI),
- \$250 million for the National Center on Minority Health and Health Disparities (NCMHD),
- Support the National Center for research resources:
  - Proportional increase for Research Centers for Minority Institutions and Institutional Development Award (IDeA) program institutions, and
  - \$119 million for extramural facilities construction.

Continue to urge NCI to support the Establishment of a Collaborative Minority Health Comprehensive Research Center at a Historically Minority Institution in collaboration with the existing NCI cancer centers. continue to urge NCI and NCMHD to collaborate on the Establishment of a Minority Health Comprehensive Research Center.

\$65 million for the Department of Health and Human Services' Office of Minority Health, and

- Urge support for the Health Professions Leadership Development and Support program at the Charles Drew University.

\$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions program.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present you with testimony. The Charles Drew University is distinctive in being the only dually designated Historically Black Graduate Institution and Hispanic Serving Institution in the Nation. We would like to thank you and your predecessors,

Mr. Chairman, for the support that this subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers over the years, NIH has been and continues to be invaluable to our university and especially our community.

The Charles Drew University is located in the Watts-Willowbrook area of South Los Angeles. Its mission is to prepare predominantly minority doctors and other health professionals to care for underserved communities with compassion and excellence through education, clinical care, outreach, pipeline programs and advanced research that makes a rapid difference in clinical practice. In our over 35 years of enrolling students, the university has become a significant source of Latino and African American doctors and health professionals. We have made a measurable contribution to improving health care in this Nation by graduating over 400 physicians, 2,000 physician assistants, 2,500 physician specialists, and numerous other health professionals—almost all from diverse communities. Even more importantly, our graduates go on to serve underserved communities and 10 years later, over 70 percent of them are still working with people who are in most need and who have the poorest access to decent health care.

The Charles Drew University has established a national reputation for translational research that addresses the health disparities and social issues that strike hardest and deepest among urban and minority populations. As you can see, we are a unique institution, and we serve a very important constituency, which regrettably, represents a growing segment of the overall U.S. population.

Currently, The Charles Drew University is experiencing a period of positive, dynamic growth. Though our former affiliate hospital, Martin Luther King-Harbor, is experiencing difficulties, our institution is transforming and continues to make an expanding contribution to the health work force, by graduating the highest caliber

of health professionals—particularly, significant number of Latinos and African Americans, who are highly sought after for employment and further training positions. Many serve in our community where recent circumstances and public health budget cuts have reduced the number of beds and physicians back to the low level that existed in 1965, when the voiceless community of South Los Angeles was forced to rebel in order to get the health and social resources it deserves.

Our university continues to flourish and garner respect and support from our colleagues, community partners and those we serve. After 30 years, in partnership with the University of California, we are establishing our own 4-year medical school and a new School of Nursing to prepare nurses as well as nursing faculty—particularly from minority populations. The Charles Drew University remains a beacon of hope for our students and our community as we have been since we began when we rose out of the ashes of the 1965 Watts civil unrest.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

##### *Title VII Health Professions Training Programs*

The health professions training programs administered by the Health Resources and Services Administration (HRSA) are the only Federal initiatives designed to address the longstanding under representation of minorities in health careers. HRSA's own report, "The Rationale for Diversity in the Health Professions: A Review of the Evidence," found that minority health professionals disproportionately serve minority and other medically underserved populations, minority populations tend to receive better care from practitioners of their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health professions institutions, they are significantly more likely to: (1) serve in medically underserved areas, (2) provide care for minorities, and (3) treat low-income patients.

HRSA's Minority Centers of Excellence (COE) and Health Careers Opportunity Program (HCOP) support health professions institutions with a historic mission and commitment to increasing the number of minorities in the health professions.

Mr. Chairman, in fiscal year 2006 these programs were cut by over 50 percent. Unfortunately, those cuts were sustained in the funding resolution passed earlier in this Congress. Looking ahead a decade, as you have encouraged your colleagues and us to do, the cuts of recent years to these programs will seriously hamper our ability to provide the desperately needed healthcare advances for our citizens. Those cuts will widen the health disparities gap that is already far too wide, and they will exacerbate the already present national physician shortage, particularly in urban areas.

##### *Minority Centers of Excellence*

The purpose of the Minority Centers of Excellence (COE) program is to assist schools, like Charles Drew University, that train minority health professionals, by supporting programs of excellence. The COE program focuses on improving student recruitment and performance; improving curricula and cultural competence of graduates; facilitating faculty and student research on minority health issues; and training students to provide health services to minority individuals by providing clinical teaching at community-based health facilities. For fiscal year 2008, the funding level for Minority Centers of Excellence should be \$33.6 million (an increase of \$21.8 million over fiscal year 2007).

##### *Health Careers Opportunity Program*

Grants made to health professions schools and educational entities under Health Careers Opportunity Program (HCOP) enhance the ability of individuals from disadvantaged backgrounds to improve their competitiveness to enter and graduate from health professions schools. HCOP funds activities that are designed to develop a more competitive applicant pool through partnerships with institutions of higher education, school districts, and other community based entities. HCOP also provides for mentoring, counseling, primary care exposure activities, and information regarding careers in a primary care discipline. Sources of financial aid are provided to students as well as assistance in entering into health professions schools. For fiscal year 2008, the HCOP funding level of \$35.6 million is suggested (an increase of \$31.6 million).

## NATIONAL INSTITUTES OF HEALTH'S CONTRIBUTION TO FIGHTING HEALTH DISPARITIES

Racial and ethnic disparities in health outcomes for a multitude of major diseases in minority and underserved communities continue to plague a Nation that was built on the premise of equality. As articulated in the Institute of Medicine report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," this problem is not getting better on its own. For example, African American males develop cancer 15 percent more frequently than their white counterparts. While African American women are not as likely as white women to develop breast cancer, they are much more likely to die from breast cancer once it is detected. In fact, according to the American Cancer Society, those who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care, typically experience high cancer incidence and mortality rates. Similarly to African American populations, Latino communities offer much higher incidences of heart disease, diabetes, obesity and some cancers than white populations. These devastating statistics beg for more research dollars and better access to quality clinical resources to address the deep-seated problems.

In response to these and similar findings in our own community and across the Nation, The Charles Drew University has been working to build a new Life Sciences Research Facility on its campus. The Center will specialize in providing not only cutting-edge research but associated medical treatments for the community that focus on prevention and the development of new strategies in the fight against cancer. These strategies will be disseminated locally and nationally to communities at risk, as well as to others engaged in comprehensive cancer prevention programs everywhere.

Mr. Chairman, as I mentioned earlier, the support that the subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers has been and continues to be critical to the effectiveness of our university and our community. The dream of a state-of-the-art research facility to aid in the fight against cancer and other diseases in our underserved community would be infeasible in our disadvantaged location without the resources of NIH.

To help establish the Life Sciences Research Building and expand our innovative translational research activities that focus on improving the health of underserved communities, The Charles Drew University is requesting increased congressional support for the National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), the National Cancer Institute (NCI), Health Resources and Services Administration (HRSA) and the Department of Health and Human Services' Office of Minority Health.

*National Center for Minority Health and Health Disparities*

The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between under-represented minority and non minority populations. The NCMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, telemedicine technology and other learning resources. The NCMHD also supports biomedical research focused on eliminating health disparities and developed a comprehensive plan for research on minority health at NIH. Furthermore, the NCMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the COE program and HCOP.

For fiscal year 2008, \$250 million is recommended for NCMHD to support these critical activities.

*Research Centers At Minority Institutions*

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources (NCRR) has a long and distinguished record of helping institutions like The Charles Drew University develop the research infrastructure necessary to be leaders in the area of translational research focused on reducing health disparities research. Although NIH has received some budget increases over the last 5 years, funding for the RCMI program has not increased by the same rate. The new Clinical and Translational Research Applications (CTSA) essentially preclude smaller institutions such as RCMI and IDeA schools to compete and link to the CTSA roadmap. We request an additional \$40 million to support a CTSA-like roadmap mechanism for RCMI and IDeA schools, and \$9.5 million to support the RCMI Translational Research Network, and also small grant mechanisms to fund pilot studies linked to the NIH Roadmap, the newly developed Global Alliance for HIV/AIDS, and community centers of health research and education excellence. This is a total of an additional \$49.5 million in fiscal year 2008.

*Extramural Facilities Construction*

Mr. Chairman, one issue that sets The Charles Drew University and many minority-dedicated institutions apart from the major universities of this country is the facilities where research takes place. The need for research infrastructure at our Nation's minority serving institutions must also remain strong to maximize efforts to reduce health disparities. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources (NCRR) is \$250 million. The law also includes a 25 percent set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. Also, the law allows the NCRR director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation in order to ensure the continued growth of relevant research from our minority health professions training schools.

Unfortunately, funding for NCRR's Extramural Facility Construction program was completely eliminated in the fiscal year 2006 Labor-HHS bill, and funding was not restored in the fiscal year 2007 funding resolution. In fiscal year 2008, we respectfully request the restoration of funding for this program to the fiscal year 2004 level of \$119 million.

## DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH

Specific programs at OMH include:

- Assisting medically underserved communities,
- Supporting conferences for high school and undergraduate students to interest them in health careers, and

- Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

OMH has the potential to play a critical role in addressing health disparities. Unfortunately, OMH does not yet have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations.

One recent OMH pilot project is the Health Professions Leadership Development and Support Program, which is designed to enhance faculty recruitment and retention support for academicians providing for the supervision, instruction, and guidance of resident physicians-in-training in underserved communities. This is a critical program for improving the minority pipeline filling a gap outlined in the report by a committee chaired by former Secretary of the Department of Health and Human Services (HHS),

Dr. Louis Sullivan titled "Missing Persons: Minorities in the Health Professions September 20, 2004." This report highlights the critical role played by institutions such as The Charles Drew University as a major training site for minority health care professions and biomedical scientists.

For fiscal year 2008, I recommend a funding level of \$65 million for OMH to support these critical activities.

## STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS—DEPARTMENT OF EDUCATION

The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2008, an appropriation of \$65 million (an increase of \$7 million over fiscal year 2007) is suggested to continue the vital support that this program provides to historically black graduate institutions.

## CONCLUSION

Despite all the knowledge that exists about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the gap continues to widen. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventative care and research are inaccessible either due to distance or lack of facilities and expertise. As noted earlier, in just one underserved area, South Los Angeles, the number and distribution of beds, doctors, nurses and other health professionals are as parlous as they were at the time of the Watts Rebellion, after which the McCone Commission attributed the so-named "Los Angeles Riots" to poor services—particularly access to affordable, qual-

ity healthcare. The Charles Drew University has proven that it can produce excellent health professionals who “get” the mission—years after graduation they remain committed to serving people in the most need. But, the university needs investment and committed increased support from Federal, State, and local governments and is actively seeking foundation, philanthropic and corporate support.

Even though institutions like The Charles Drew University are ideally situated (by location, population, community linkages and mission) to study conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, the Life Sciences Research Facility will translate insight gained through research into greater understanding of disparities and improved clinical outcomes. Additionally, programs like Title VII Health Professions Training programs will help strengthen and staff facilities like our Life Sciences Research Facility.

We look forward to working with you to lessen the huge negative impact of health disparities on our Nation’s increasingly diverse populations, the economy and the whole American community.

Mr. Chairman, thank you again for the opportunity to present testimony on behalf of The Charles Drew University. It is indeed an honor.

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PREPARED STATEMENT OF THE COALITION FOR THE ADVANCEMENT OF HEALTH  
THROUGH BEHAVIORAL AND SOCIAL SCIENCE RESEARCH

Mr. Chairman and members of the subcommittee, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the fiscal year 2008 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 16 professional organizations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

The behavioral and social sciences regularly make important contributions to the well-being of this Nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the Nation’s battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. As a result of the strong congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH’s behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

To ensure that progress is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting a fiscal year 2008 appropriation of \$30.8 billion for the NIH, a 6.7 percent increase over fiscal year 2007. This level of funding will provide adequate resources to sustain the momentum of the recently completed campaign to double the Nation’s investment in the promising research supported and conducted by the NIH. Unfortunately, the President’s request does not allow us to fully reap the research opportunities that the doubling campaign have made available.

Nearly 125 million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer’s disease. The Centers for Medicare and Medicaid Services (CMS) recently reported that health care spending in the United States rose to \$1.6 trillion in 2002, up from \$1.4 trillion in 2001 and \$1.3 trillion in 2000. Health expenditures per person averaged \$5,440 in 2002, up from \$5,021 in 2001 and \$4,670 in 2000. Today, it is even more. Significant factors driving this increase are the aging of the U.S. population, and the rapid rise in chronic diseases, many caused or exacerbated by behavioral factors: for example, obesity, caused by sedentary behavior and poor diet; addictions and resulting health problems caused by tobacco and other drug use.

Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur. NIH supports behavioral and social science research throughout most of its 27 institutes and centers. Numerous reports by the National Academy of Sciences (e.g. The Aging Mind, New Horizons in Health: An Integrative

Approach, and Health and Behavior) have presented cutting edge research agendas and made eloquent cases for the applicability of the social and behavioral scientific disciplines to the myriad, complex problems of prevention, treatment and cure of diseases as well as the enhancement of quality of life.

CAHT-BSSR supports an appropriation of \$27.8 million for NIH Office of Behavioral and Social Sciences Research, an increase of 6.7 percent, commensurate with an overall increase of 6.7 percent for the NIH. OBSSR's purpose is to serve a convening and coordinating role among the institutes and centers at NIH. The Office was authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995.

As highlighted by NIH Director Elias Zerhouni on the occasion of OBSSR's 10th anniversary in June 2006, "the OBSSR has been a tremendous asset to NIH throughout its first 10 years . . . we are faced with an enormous and evolving national burden of disease and disability, much of which has roots in personal behavior or socioeconomic influences. The need for behavioral and social research and intervention has never been greater, and its impact has never been clearer. We need but look at recent decreases in rates of cancer, largely due to dramatic decreases in tobacco use. We can point to a remarkable demonstration of the pronounced benefits of diet and exercise—more effective than drug therapy—in preventing the onset of type 2 diabetes among high-risk individuals. These are but two among many shining examples of the widespread benefits to public health realized through our investment in basic and applied behavioral and social science research, so critical to our understanding of health and disease.

OBSSR focuses on cross-cutting behavioral and social research issues (e.g. "Long-term Maintenance of Behavior Change") using its modest budget to seed cross-institute research initiatives. OBSSR has spurred cutting edge research in areas such as measures of community health, socioeconomic status, and new methodology development. The Office has been able to leverage substantive funding initiatives with a small budget.

In fiscal year 2008, OBSSR plans to work with the 27 NIH Institutes and Centers (ICs) to initiate two new programs. The first program is in the area of health disparities. The Behavioral and Social Science Contributions to Understanding and Reducing Health Disparities will be designed to support trans-disciplinary research involving teams of behavioral, social, and biomedical scientists, on prevention, policy, and health care. The research program will emphasize both basic research on the behavioral, social, and biomedical pathways, giving rise to disparities in health and applied research on the development, testing, and delivery of interventions to reduce disparities in the areas of policy, prevention, and health care.

The second initiative planned by OBSSR is in the area of Genes, Behavior and the Social Environment. OBSSR plans to work across the institutes and centers to consider the recommendations from the Institute of Medicine's report, *Genes, Behavior, and the Social Environment, Moving Beyond the Nature/Nurture Debate*, commissioned by OBSSR, along with the National Institute of General Medical Sciences (NIGMS) and the National Human Genome Research Institute (NHGRI). The report identifies gaps in knowledge and barriers that hamper the integration of social, behavioral, and genetic research.

The IOM panel recognized "that understanding the association between health and interactions among social, behavioral, and genetic factors require research that embraces the systems view and includes an examination of the interactive pathways through which these fields operate to affect health." Such research requires the participation of scientific investigators from a variety of fields and a shift in focus from efforts that are dominated by single disciplines to research that involves collaborative participation of scientists from various expertise at all stages of the research process. Below are the IOM's 14 recommendations.

1. *Conduct Trans-disciplinary, Collaborative Research.*—The NIH should develop Requests for Applications (RFAs) to study the impact on health of interactions among social, behavioral, and genetic factors and their interactive pathways (i.e., physiological).

2. *Measure Key Variables Over the Life Course and Within the Context of Culture.*—NIH should develop RFAs for studies of interactions that incorporate measurement, over the life course and within the context of culture, of key variables in the important domains of social, behavioral, and genetic factors.

3. *Develop and Implement New Modeling Strategies to Build More Comprehensive, Predictive Models of Etiologically Heterogeneous Disease.*—NIH should emphasize research aimed at developing and implementing such models (e.g., pattern recognition, multivariate statistics, and systems-oriented approaches) for incorporating social, behavioral, and genetic factors, and their interactive pathways in testable models within populations, clinical settings, or animal studies.

4. *Investigate Biological Signatures.*—Researchers should use genomic, transcriptomic, proteomic, metabonomic, and other high dimensional molecular approaches to discover new constellations of genetic factors, biomarkers, and mediating systems through which interactions with social environment and behavior influence health.

5. *Conduct Research in Diverse Groups and Settings.*—NIH should encourage research on the impact of interactions among social, behavioral, and genetic factors and their interactive pathways on health that emphasizes diversity in groups and settings. NIH should also support efforts to ensure that the findings of such research is validated by replication in independent studies, translated to patient-oriented research, conducted and applied in the context of public health, and used to design preventive and therapeutic approaches.

6. *Use Animal Models to Study Gene-Social Environment Interaction.*—NIH should develop RFAs that use carefully selected animal models for research on the impact on the impact of interactions among social, behavioral, and genetic factors and their interactive pathways.

7. *Advance the Science of Study of Interactions.*—Researchers should base testing for interaction on a conceptual framework rather than simply the testing of a statistical model, and they must specify the scale (e.g., additive or multiplicative) used to evaluate whether or not interactions are present. NIH should develop RFAs for research on developing study designs that are efficient at testing interactions, including variation in interactions over time and development.

8. *Expand and Enhance Training for Trans-disciplinary Researchers.*—NIH should use existing and modified training tools both to reach the next generation of researchers and to enhance the training of current researchers. Approaches include individual fellowships and senior fellowships, trans-disciplinary institutional grants, and short courses.

9. *Enhance Existing and Develop New Datasets.*—NIH should support datasets that can be used by investigators to address complex levels of social, behavioral, and genetic variables and their interactive pathways. This should include enhancement of existing datasets that already provide many, but not all of the needed measures and the encouragement of their use. NIH should also develop new datasets that address specific topics that have high potential for showing genetic contribution, social variability, and behavioral contributions—topics such as obesity, diabetes, and smoking.

10. *Create Incentives to Foster Trans-disciplinary Research.*—NIH and universities should explore ways to create incentives for the kinds of team science needed to support trans-disciplinary research.

11. *Communicate with Policymakers and the Public.*—Researchers should (1) be mindful of public and policymakers' concerns; (2) develop mechanisms to involve and inform these constituencies; (3) avoid overstating their scientific findings; and (4) give careful consideration to the appropriate level of community involvement and the level of community oversight needed for such studies.

12. *Expand the Research Focus.*—NIH should develop RFAs for research that elucidates how best to encourage people to engage in health—promoting behaviors that are informed by a greater understanding of these interactions; how best to effectively communicate research results to the public and other stakeholders; and how best to inform research participants about the nature of the investigation (gene-environment interactions) and the uses of data following the study.

13. *Establish Data-Sharing Policies That Ensure Privacy.*—Institutional Review Boards and investigators should establish policies regarding the collection, sharing, and use of data that include information about: (1) whether and to what extent data will be shared; (2) the level of security to be provided by all members of the research team as well as the research and administrative process; (3) the use of state-of-the-art security data in ways that are consistent with those agreed to by the research participants.

14. *Improve Informed Consent Process.*—Researchers should ensure that informed consent includes the following: (1) descriptions of the individual and social risks and benefits of the research; (2) the identification of which individual results participants will and will not receive; (3) the definition of the procedural protections that will be provided, including access policies and scientific oversight; and (4) specific security, privacy, and confidentiality protections to protect the data and samples of research participants.

Implementing the IOM's recommendations would go a long ways towards helping to realize the ultimate goal of personalized health care, one of Secretary Michael Leavitt's priorities. Personalization needs to reflect genes, behaviors, and environments. Assessing behavior is critical to helping individuals see how they can improve their health. It is also critical to helping health care see where it needs to

put resources for behavior change. As noted by Dr. Zerhouni, "Right now, everyone is focused on finding the magic answer. But health care is different from region to region across the country." Full personalization needs to consider the environmental, community, and neighborhood circumstances that govern how individuals' genes and behavior will influence their health. For personalized health to be realized, we need a sophisticated understanding of the interplay between genetics and the environment, broadly defined.

CAHT-BSSR would be pleased to provide any additional information on these issues. We have attached a list of coalition member societies to the end of the testimony. We thank the subcommittee for its generous support of the National Institutes of Health and for the opportunity to present our views.

#### CAHT-BSSR MEMBERS

American Educational Research Association; American Psychological Association; American Sociological Association; Association of Population Centers; Center for the Advancement of Health; Consortium of Social Science Associations; Gerontological Society of America; Institute for the Advancement of Social Work Research; National Association of Social Workers; National Council on Family Relations; National Mental Health Association; Population Association of America; Sex Information and Education Council of the United States; Society for Public Health Information; Society for Research in Child Development; and The Alan Guttmacher Institute.

#### PREPARED STATEMENT OF THE COALITION FOR AMERICAN TRAUMA CARE

The Coalition for American Trauma Care is pleased to provide its recommendations for fiscal year 2008 appropriations for public health programs that support trauma care, trauma care research, and injury prevention.

The Coalition for American Trauma Care is a nonprofit association of national health and professional organizations that seeks to improve care for the seriously injured patient through improved delivery of trauma care services, research and rehabilitation activities. The Coalition also supports efforts to prevent injury from occurring.

Injury is one of the most important public health problems facing the United States today. It is the leading cause of death for Americans from age 1 through age 34. More than 145,000 people die each year from injury, 88,000 from unintentional injury such as car crashes, fires, and falls, and 56,000 from violence-related causes. Over 85 children and young adults die from injuries in the United States every day translating into 30,000 deaths annually. Injury is also the most frequent cause of disability. Millions of Americans are non-fatally injured each year leaving many temporarily disabled and some permanently disabled with severe head, spinal cord, and extremity injuries. Because injury so often strikes the young, injury is also the leading cause of years of lost work productivity and, at an estimated \$224 billion in lifetime costs each year, trauma is our Nation's most costly disease.

*Trauma Care Systems.*—The Coalition is extremely disappointed that Congress failed to appropriate any funding for the Health Resources and Services Administration's Trauma-EMS program in fiscal year 2007 and urges the subcommittee to provide \$12 million in funding for fiscal year 2008. Congress is in the process of re-authorizing the program (H.R. 727; S. 657) at a level of \$12 million for fiscal year 2008. In recent days both the House Energy and Commerce Committee and the Senate Health, Education, Labor and Pensions Committees approved their respective bills unanimously. The Trauma-EMS program, administered by HRSA for 5 years, from fiscal year 2001–2005, provided critical national leadership which leveraged additional scarce State dollars to strengthen trauma systems so that seriously injured individuals, wherever they live, receive prompt emergency transport to the nearest appropriate trauma center within the "golden hour." Receiving appropriate, quality trauma care within 1 hour of injury saves lives and provides the best chance for a good recovery. Achieving this result takes coordination, commitment of staff, development and implementation of standards of care, a process for designating trauma centers, and evaluation.

No other program in the Federal Government addresses this critical aspect of the Nation's emergency response infrastructure. According to the Trauma-EMS Systems Program Assessment Rating Tool (PART) released by the OMB, "the Trauma Care program has demonstrated success in assisting States in adopting statewide standardized triage protocols and designating trauma centers. Studies indicate with some consistency that improving organized systems of trauma care, specifically States designating trauma centers and adopting standardized triage protocols, leads to measurable decreases in mortality due to trauma."

Despite this progress, only 8 States have fully developed trauma systems; 12 States do not even have the authority to designate trauma centers. In a recent Harris Poll, large majorities of the American public said they valued trauma centers and systems as highly as having a police or fire department in their community. We therefore request that you reinstate funding for this vital, life saving program.

*National Center for Injury Prevention and Control.*—The Coalition supports \$168 million in funding in fiscal year 2008 for the National Center for Injury Prevention and Control which is currently funded at \$138 million. The Coalition is exceedingly pleased with the support CDC has provided for the National Evaluation of the Effect of Trauma Center Care on Mortality. The results of this study, published in the January 26, 2006 New England Journal of Medicine, were that care at a trauma center lowers by 25 percent the risk of death for injured patients compared to treatment received at non-trauma centers. The NCIPC supports a range of injury prevention activities and through evaluation has proven their effectiveness in many areas. Just two examples of these: reduction of the more than 20,000 head injuries that occur every year by encouraging the use of bicycle helmets and reduction of burn-related injuries through smoke detector implementation programs.

*Traumatic Brain Injury (TBI).*—Traumatic brain injury is a leading cause of trauma-related disability. Brain injury is a silent epidemic that compounds every year, but about which still little is known. The Coalition is opposed to the proposed elimination of this important program in the President's fiscal year 2008 budget request and urges you to provide a total of \$30 million for the Traumatic Brain Injury (TBI) Act, as follows: \$9 million for CDC to strengthen State and local data collection activities, improve linkage of persons with TBI to services, increase public education and awareness, and conduct public health research related to TBI. Within the \$30 million, the Coalition also supports \$15 million for the HRSA TBI State Grant Program to ensure that every State, territory and American Indian Consortia can coordinate and maximize resources to serve their TBI population and provide training and technical assistance to grantees. Also within the \$30 million total, \$6 million is needed for the HRSA Protection and Advocacy Program for population-based allotments to all States to ensure adequate and appropriate assistance to individuals with brain injury in exercising their rights and accessing public service systems.

*Children's EMS.*—The Coalition is opposed to the proposed elimination of this program in the President's fiscal year 2008 budget request and urges you to provide \$25 million in fiscal year 2008. While this amount represents a 25 percent increase for this program, it has been flat-funded for 6 years causing an erosion in available resources due to inflation. Children currently account for up to 30 percent of all emergency department visits and 10 percent of ambulance runs annually, but many facilities lack the specialized equipment needed to care for them. Moreover, many emergency personnel do not have the necessary education or training to provide optimal care to children. In order to assist local communities in providing the best emergency care to children the Children's EMS program needs to continue and continue at a level that allows resources to keep pace with inflation.

*Preventive Health/Health Services Block Grant (PHHS).*—The Coalition is deeply disappointed that Congress cut funding in fiscal year 2006 for this program by \$32 million, or 24 percent, and that the President has proposed to eliminate funding in fiscal year 2008. The Coalition urges you to restore funding to the fiscal year 2005 of \$131 million when the subcommittee marks up its fiscal year 2008 bill. The PHHS Block Grant provides flexible funding to States to allow them to address specific health problems identified under the Healthy People 2010 assessment process. The funding allows States to take innovative approaches to address significant health issues and complements, not duplicates, some of CDC's other program activities. In addition, the PHHS Block Grant is the largest single source of Federal funding for support of basic State Emergency Medical Services' (EMS) infrastructure—the first line of defense against death and disability resulting from severe injury.

*Rural EMS Training and Equipment Program.*—The Coalition urges you to provide \$900,000 in funding for the Rural EMS Training and Equipment Program. This program was eliminated in fiscal year 2006 and needs not only restoration, but expansion in fiscal year 2008. Rural areas are in critical need of emergency medical services training and equipment. Recent national events have continued to draw attention to the need for communities to have strong emergency medical systems in place. Unfortunately, while the need for effective emergency medical care may have increased, the number of individuals able to provide these services has declined. This is a particular problem in rural areas where the majority of EMS personnel are unpaid volunteers. As rural economies continue to suffer, it has become progressively more difficult for rural EMS providers to recruit and retain these personnel. As a consequence, emergency medical squads are becoming smaller. The rural EMS training and equipment program awards competitive grants to State EMS Offices,

State Offices of Rural Health, local government, and State or local ambulance providers to improve emergency medical services in rural areas.

The funds can be used to:

- Recruit emergency and volunteer medical service personnel;
- Train emergency medical service personnel in emergency response, injury prevention, safety awareness, and other topics relevant to the delivery of emergency medical services;
- Fund specific training to meet Federal or State certification requirements;
- Develop new ways to educate emergency health care providers through the use of technology enhance educational methods (such as distance learning);
- Acquire emergency medical services equipment including cardiac defibrillators;
- Acquire personal protective equipment for emergency medical services personnel; and
- Educate the public concerning cardiopulmonary resuscitation, first aid, injury prevention, safety awareness, illness prevention, and other related emergency preparedness topics.

The Coalition for American Trauma Care is both deeply disappointed and alarmed by the President's fiscal year 2008 budget which proposes elimination of all funding for four programs specifically designed to build infrastructure to ensure that trauma and emergency medical services are available and appropriate to need: HRSA's Trauma-EMS systems program; HRSA's Traumatic Brain Injury program; HRSA's Children's EMS program and CDC's Preventive Health and Health Services Block Grant. If these cuts are enacted, the results would be devastating for emergency care in the United States for everyone and particularly for children and those who have suffered head injury. The burden of injury in America has been well documented by numerous IOM reports and injury facts speak for themselves: injury is the leading cause of death and disability for children and adults up to age 44. While much more can and needs to be done to prevent injury from occurring at all, we will never be able to eliminate it entirely. Cutting these programs will not lessen the injury burden in America; on the contrary, it will significantly increase the burden of death, disability and direct and indirect health care costs. We need to increase our investment in these program areas, not reduce our commitment.

The Coalition greatly appreciates the support the subcommittee has provided to trauma related programs in the past and looks forward to working with the subcommittee in the coming weeks and months.

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#### PREPARED STATEMENT OF THE COALITION OF EPSCoR/IDEA STATES

Thank you for the opportunity to submit this testimony in support of fiscal year 2008 funding for the National Institutes of Health's Institutional Development Award or "IDeA" Program. The IDeA program is funded by NIH's National Center for Research Resources (NCRR), and was authorized by the 1993 NIH Revitalization Act (Public Law 103-43).

My name is Dr. Peter Alfonso and I am the Vice Provost for Research, Graduate Studies and Outreach and Dean of the Graduate School at the University of Rhode Island. I submit this testimony on behalf of the Coalition of EPSCoR/IDeA States.<sup>1</sup> EPSCoR is the "Experimental Program to Stimulate Competitive Research," and IDeA, as previously stated, is the NIH's Institutional Development Award program.

IDeA is an important program because it increases our Nation's biomedical research capability by improving research in States that have historically been less successful in obtaining biomedical research funds. Twenty-three States and Puerto Rico are eligible.

IDeA funds only merit-based, peer-reviewed research that meets NIH research objectives.

As previously mentioned, IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103-43), but the program was funded at very low levels during its early years. However, between fiscal year 2000 and fiscal year 2003, IDeA grew rapidly, due in large part to the thoughtful actions of this subcommittee. This funding permitted the initiation of two new program elements:

The first was COBRE or "Centers of Biomedical Research Excellence," which are research clusters targeting specific biomedical research problems. The COBRE pro-

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<sup>1</sup>Alabama, Alaska, Arkansas, Delaware, Hawaii, Idaho, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Puerto Rico, Rhode Island, South Carolina, South Dakota, Vermont, Virgin Islands, West Virginia, and Wyoming. (States in italic letters are eligible for the IDeA program. All of the States listed above are also eligible for the EPSCoR program.)

gram is designed to increase the pool of well-trained investigators in the IDeA States by expanding research facilities, equipping laboratories with the latest research equipment, providing mentoring for promising candidates, and developing research faculty through support of a multi-disciplinary center, led by an established, senior investigator with expertise in the research focus area of the center.

The second was BRIN or "Biomedical Research Infrastructure Networks," which targeted key areas such as bioinformatics and genomics and facilitated the development of cooperative networks between research-intensive and primarily undergraduate colleges. The BRIN grants underwent competitive renewals in 2004 under the new name of IDeA Networks of Biomedical Research Excellence (INBRE). The INBRE program prepares students for graduate and professional schools as well as careers in the biomedical sciences, supports research and mentoring of young investigators, and enhances research infrastructure at participating institutions.

Although IDeA is relatively new, there is already objective evidence of its success. In fiscal year 1999, the year before COBRE grants were initiated, IDeA States received a total of \$595 million from NIH. In fiscal year 2005, NIH funding for the IDeA States had increased to \$1.556 billion, representing an increase of 162 percent in 6 years. It is important to note, however, that in the following year as the IDeA budget started to decrease, NIH funding for the IDeA States fell to \$1.458 billion, the same level as in fiscal year 2003.

I would like to describe a few examples of how both COBRE and INBRE (formerly BRIN) grants have changed the biomedical research landscape of Rhode Island. The first COBRE award in Rhode Island was made to Brown University in 2000. Prior to this award the biomedical research infrastructure of the University was severely lacking and the interactions between researchers at Brown and at other institutions within the State were minimal at best.

The COBRE award allowed the PI to fund five promising junior investigators, all of whom won subsequent major NIH grants by the end of the award period. State-of-the-art core facilities in microscopy, genomics, and transgenics were established and staffed with Ph.D. level directors. Seminar series and workshops were initiated with COBRE funding, and served as the basis for developing collaborative ties with researchers throughout the State. COBRE funding also was directly translated into the establishment of a "Center for Genomics and Proteomics" at Brown that included the purchase and renovation of significant new research space in an old industrial section of the city. This area of the city has now been filled with new businesses and is prospering.

The 2000 COBRE award was renewed for another 5 years and the focus is now on signaling and cancer, with the long term goal of establishing a cancer center. Since the first COBRE award to Brown University in 2000, three other COBREs have been awarded to three separate institutions: Rhode Island Hospital, Roger Williams Hospital, and Women and Infants Hospital. In all three cases, the awarded funds have directly led to the establishment of critical Core Facilities that provide new faculty with valuable access to state-of-the-art instrumentation that they would not be able to acquire through standard grant award mechanisms. For all of these reasons, COBRE is a critical mechanism of support for States with limited budgets for research support.

The 3-year BRIN grant, awarded to Rhode Island in 2001 and competitively renewed as INBRE for 5 years in 2004, provided another mechanism for addressing both the lack of critical mass of biomedical researchers at the University of Rhode Island and other primarily undergraduate institutions in the States, and the lack of high-end state-of-the-art equipment for biomedical research at these institutions. Lack of critical mass and the necessary infrastructure to support biomedical research meant that existing researchers were unable to perform cutting edge research and effectively compete for research dollars from Federal agencies such as the National Institutes of Health. Meager startup funds available for hiring new faculty hampered efforts to recruit quality research-oriented faculty. There were limited opportunities for student training in faculty laboratories, and finally, there was a lack of the type of interinstitutional cooperation needed to create a network of biomedical researchers.

Through funding received as a result of the BRIN/INBRE awards, more than \$2 million in biomedical research equipment for genomics, proteomics and drug development studies has been purchased and housed in a renovated laboratory. This equipment is accessible to all researchers from the participating institutions: University of Rhode Island; Rhode Island College; Providence College; Roger Williams University; Salve Regina University; and Brown University. Through BRIN/INBRE funding, the Center for Molecular Toxicology at the University of Rhode Island was established. The Center has allowed us to leverage the creation of new faculty positions at all participating institutions in the related thematic areas of toxicology, cell

biology and environmental health, and helped provide competitive new faculty start-up packages. New faculty research, coupled with regularly scheduled seminars and workshops, is generating increased student interest in research and also greater training opportunities for students in faculty laboratories. Greater student training in turn translates into workforce development in the biomedical and biotechnological fields.

The Rhode Island BRIN/INBRE awards have led to the creation of an effective state-wide collaborative network of biomedical researchers, which is essential for implementing an environment that will foster collaborative research. Finally, and most importantly, this funding has helped biomedical researchers in our State to achieve greater success in competing for Federal research dollars. This is the ultimate goal of the IDeA program.

Despite these successes, our task is far from complete. Funding disparities between the States remain and may have a detrimental impact on our national self-interest. And that is why the IDeA program is so important. It is helping to ensure that all regions of the country participate in biomedical research. Citizens from all States should have the opportunity to benefit from the latest innovations in health care, which are most readily available in centers of biomedical research excellence.

For this reason, I am deeply concerned by the fiscal year 2008 Budget Request for the IDeA program. The fiscal year 2008 Budget Request for the IDeA program is \$210,963,000, which is a \$9,023,000 decrease from the fiscal year 2006 level of funding for the program. This is the second year in a row that the IDeA program has been cut in the President's Budget. The fiscal year 2007 budget request was the first time since 1993 that the budget request for IDeA was below the previous year's appropriated level for the program.

I applaud the efforts your subcommittee has made over the years to provide increased funding for IDeA, and hope that you will continue to invest in this program, which is so important to almost half of our States. The cut proposed in the fiscal year 2008 budget request will have a crippling effect on the biomedical research centers, researchers and students in IDeA States. The IDeA program is important to so many in our States, but especially to the junior investigators who are starting to become competitive for NIH funding. I think we send these young investigators the wrong message by cutting or even possibly eliminating funding for their research projects after encouraging them to pursue a career in biomedical research.

For this reason, the Coalition of EPSCoR/IDeA States believe the program should be funded at \$250 million in fiscal year 2008. This level of funding would restore and continue funding for COBRE and INBRE, provide funding for information technology (IT) infrastructure upgrades through IDeANet, and also, some funding would be used for a co-funding program, which would allow researchers and institutions to merge with the overall national biomedical research community.

By any reasonable standard, an already proven "IDeA" for increasing biomedical research capacity in a cohort of States which comprise one-sixth of our population and yet still receive barely one-twentieth of the NIH budget, deserves increased support. I am sensitive to the tough budget environment that NIH has faced over the past 4 years. Yet, when I consider that in 2005, the top 7 States that were recipients of NIH funding received over a \$1 billion each, California alone received over \$3 billion, \$250 million for 23 States and Puerto Rico seems more than reasonable. Every region of the country has talent and expertise to contribute to our Nation's biomedical research efforts—and every region of the country must participate if we are to increase our Nation's biomedical research capacity substantially. On behalf of the Coalition of EPSCoR/IDeA States, I thank the subcommittee for the opportunity to submit this testimony.

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#### PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding is pleased to provide the subcommittee with its testimony recommending fiscal year 2008 funding levels for the agencies and programs of the U.S. Public Health Service. Since 1970, the Coalition's member organizations, representing 40 million health care professionals, researchers, patients and families, have been advocating for sufficient resources for PHS agencies and programs to meet the changing health challenges confronting the American people. One of the important principles that unites the Coalition's members is that the health needs of the Nation's population must be addressed by strong, sustained support for a continuum of activities that includes biomedical, behavioral and health services research; community-based disease prevention and health promotion; health care services for vulnerable and medically underserved populations; ensuring a safe and

effective food and drug supply; and education of a health professions workforce in adequate numbers to address the breadth of need.

The Coalition for Health Funding believes the Bush administration, and Congress, have undermined progress that has been made and also missed an important opportunity to improve the health of all Americans by reducing rather than investing more resources in the agencies and programs of the U.S. Public Health Service. Federal spending for public health has always been low compared to other health spending, amounting to 3 percent of total health care spending according to the Centers for Medicare and Medicaid, and yet an investment in public health has the potential to slow unsustainable growth in mandatory costs, reduce lost productivity at work, school and home, and strengthen every citizen's contribution for a healthy, economically strong America.

Instead of investing in these proven approaches, in recent years we have seen serious erosion of resources. Last year, through the strong efforts of a few House and Senate Members of Congress working with the advocacy community, the bleeding was staunch somewhat through the addition of \$7 billion in funding for the agencies and programs under the jurisdiction of the Labor-HHS-Education Appropriations Subcommittees. However, as the table below shows, health agencies did not benefit across the board, with CDC, HRSA and SAMHSA funded in the final fiscal year 2007 Joint Resolution below fiscal year 2005 by a total of \$837 million. In addition, all of the health agencies still face shortfalls when compared with fiscal year 2005 when inflation is accounted for. The President's fiscal year 2008 budget request cuts even more deeply—another \$1.1 billion below fiscal year 2007 and a full \$1.6 billion below fiscal year 2005.

The Coalition for Health Funding urges the subcommittee to reject the President's proposal to reduce the Nation's investment in public health and instead join over 400 health organizations that, in letter dated February 26, urged Congress to make an investment in public health of \$4 billion over fiscal year 2007 levels. As that letter states:

"The investment in disease prevention and health promotion for all Americans needs to grow, as our Nation struggles with escalating health care costs, growing numbers of uninsured, and the prospect of declining health measured by overall morbidity and mortality. Over the past 4 years we have seen a decrease in that investment. The President's budget for fiscal year 2008 continues to seriously underfund and undermine an important part of the solution: public health activities and programs.

While the final fiscal year 2007 funding resolution provided needed increases to selected programs, most public health programs were held at fiscal year 2006 funding levels. The undersigned organizations urge you to increase funding for public health through the Function 550/discretionary budget allocation in fiscal year 2008 by an amount that will restore funding cuts to public health programs enacted in fiscal year 2006, and restore lost purchasing power. It is estimated that an additional \$4 billion, 7.8 percent, will be needed in fiscal year 2008 to meet that goal and reverse the erosion of support for the continuum of biomedical, behavioral and health services research, community-based disease prevention and health promotion, basic and targeted services for the medically uninsured and those with disabilities, health professions education, and robust regulation of the Nation's food and drug supply."

The following is a partial list of the Coalition's fiscal year 2008 recommendations for specific U.S. Public Health Service agencies. The Coalition developed these recommendations working with eight other health coalitions with a more targeted focus on one agency.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

The Coalition supports \$30.869 billion in fiscal year 2008 for the National Institutes of Health, a 6.7 percent increase over the fiscal year 2007 funding level. This recommendation begins a 3 year process for restoring NIH's purchasing power following 4 years of flat funding at the end of the doubling in fiscal year 2003. The President's fiscal year 2008 budget request, by contrast, cuts NIH \$310 million below fiscal year 2007. Enactment of the administration's proposal would mean about a 13 percent cut in inflation-adjusted dollars in the biomedical research capacity of our Nation. The result is NIH is funding fewer research projects, slowing our progress against disease and disability and discouraging talented young people from pursuing careers in medical research. Scientific discoveries are the result of a series of incremental steps that pave the way for future breakthroughs. This process needs sustained support.

## CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The Coalition for Health Funding recommends a level of \$7.7 billion for CDC's core programs in fiscal year 2008. This amount is \$1.6 billion more than the fiscal year 2007 funding level and \$1.8 billion more than the President's request for fiscal year 2008. This amount reflects CDC's professional judgment for core CDC programs that address prevention of chronic diseases, infectious diseases including adult and child immunization, and support for basic public health infrastructure. CDC is the Nation's primary investment in disease prevention and health promotion. Since fiscal year 2005, the agency's core programs have lost \$500 million in funding. It is astounding this decline has been allowed to occur when the Nation faces the challenge of galloping obesity and its ensuing costly chronic disease; new and emerging infectious diseases like West Nile virus and those caused by antimicrobial resistant bacteria; vaccine-preventable diseases that occur every day; still growing numbers of Americans with HIV, with an estimated 250,000 who do not know they are infected; and a public health infrastructure that still needs shoring up after decades of neglect and that is facing massive loss of its trained workforce. One example that summarizes the shocking condition of core CDC programs is the National Center for Health Statistics (NCHS). Due to a shortfall of a mere \$3 million in fiscal year 2007, NCHS does not have the funding it needs to collect vital birth and death statistics from States for the last 3 months of this calendar year. If this is not addressed, the United States will be the first industrialized Nation in the world unable to collect this information, and as Rep. Rosa DeLauro, a member of the House Labor-HHS-Education Subcommittee on Appropriations commented, "... [this will] compromise our ability not only to target our own public health interventions and evaluate our health standing on the international stage, but also monitor causes of death, including infectious diseases like influenza. As you know, death records are the first line of defense in our preparedness system, serving as the warning bell for a pandemic outbreak."

## HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The Coalition for Health Funding recommends an overall funding level of \$7.5 billion for HRSA in fiscal year 2008. This amount is \$617 million, or 8.9 percent, more than the fiscal year 2007 funding level, and is \$1.7 billion more than the President's request. This is the amount that the Coalition believes is needed to provide adequate resources for the important programs that HRSA administers.

The Coalition is extremely concerned about recent deep cuts in funding to HRSA, the Federal agency whose central stated mission is to achieve 100 percent access to health care services with zero disparities. This is simply not achievable with a cut of over 6 percent in fiscal year 2006 and a proposed additional cut of 8.5 percent in the President's fiscal year 2008 budget. Chief among the cuts enacted in fiscal year 2006, and proposed for complete elimination in the President's budget request, are the Title VII Health Professions education programs. In addition, the President's fiscal year 2008 budget cuts the Title VIII nursing education programs by \$44 million, or nearly 30 percent. The Title VII and the Title VIII nursing education programs are the only Federal programs designed to train providers in multidisciplinary settings to meet the needs of special and underserved populations, as well as increase the minority representation in the health care workforce. Cuts imposed in fiscal year 2006 of 51.5 percent, including elimination of 7 Title VII programs, will only exacerbate racial and geographic disparities. Graduates of these programs are 3–10 times more likely to practice in underserved areas and are 2–5 times more likely to be minorities. The Coalition urges the subcommittee to restore funding levels for Title VII to the fiscal year 2005 level, and not only reject proposed cuts for Title VIII, but increase funding for this program addressing well-documented nursing shortages.

The Coalition also rejects the proposed 63 percent cut in Children's Hospitals Graduate Medical Education. Children's hospitals do not have access to Medicare funds to help train physicians that care for sick children.

The Coalition deplores the elimination of several other HRSA programs in fiscal year 2006 including the Trauma-EMS Systems program, which supports States in the development of systems to ensure severely injured individuals receive quality trauma care in a timeframe that ensures optimal outcomes, and the Healthy Community Access program and State planning grants designed to close gaps in access to health care for uninsured individuals. Proposed elimination in the President's fiscal year 2008 budget of the Children's EMS program, the Traumatic Brain Injury program, the Universal Newborn Screening program, the Rural and Community Access to Emergency Devices program to train lay rescuers and first responders to use Automated External Defibrillators, and a 90 percent cut for the Office of Rural

Health Policy diminish both targeted prevention activities and health care access. Further, a cut of \$31 million in fiscal year 2006 to the Maternal and Child Health program, followed by a hard freeze in fiscal year 2007 and a proposed freeze in the President's fiscal year 2008 budget request, has reduced services across the Nation to the more than 26 million pregnant women, infants and special needs children served by the MCH Block Grant. MCH programs increase immunizations, newborn screening, reduce infant mortality and developmentally handicapping conditions, prevent childhood accidents and injuries, and reduce adolescent pregnancy.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

The Coalition for Health Funding recommends an overall funding level of \$3.532 billion for SAMHSA in fiscal year 2008. This amount is \$207 million, or 6.2 percent, more than the fiscal year 2007 funding level, and \$364 million more than the President's budget request, which includes a \$157 million cut for SAMHSA programs.

Despite the recent release of the Federal "Action Agenda" to ensure that people with mental illness have every opportunity for recovery, the President's fiscal year 2008 budget proposes to cut mental health services by \$77 million, or 8.7 percent, following a cut in fiscal year 2006 of \$17 million. This means that the charge from the President's New Freedom Commission on Mental Health for transforming the mental health system cannot occur if SAMHSA funding continually erodes. The need to make mental health a national priority is nowhere better illustrated than in the shocking rates of suicide and suicide attempts in the United States despite the Commission's finding that suicides are "a largely preventable public health problem." According to CDC, the suicide rate among U.S. residents younger than age 20 increased by 18 percent from 2003–2004, the only cause of death for teens that increased. Up to 35,000 children displaced by Hurricane Katrina in 2005 are having emotional, behavioral or school problems with a fourfold increase in those diagnosed with clinical depression or anxiety and a doubling of behavioral, or conduct problems after the hurricane. A proposed fiscal year 2008 mental health budget that is less than it was in fiscal year 2003 does not allow SAMHSA to meet existing needs, let alone respond to the consequences following a disaster.

The Coalition is disappointed that the President's fiscal year 2008 budget proposes cuts in funding for substance abuse programs by \$84 million and recommends a \$100 million increase for the Substance Abuse Treatment and Prevention Block Grant and a \$15 million increase for discretionary treatment programs and a \$17 million increase for discretionary prevention programs. Substance abuse is a significant and very costly national problem involving an estimated 21.6 million Americans—over 9 percent of the population—and needs investment in both treatment and prevention. Currently only 18 percent of all Americans over the age of 12 who need treatment receive it. Emerging trends also need specific attention: returning veterans with mental health and substance abuse problems that are not eligible for VA services, or will not use them due to stigma; and growing methamphetamine addiction. Clearly, a stronger investment for this problem, which is estimated to cost the Nation \$346 billion, is needed.

The Coalition appreciates this opportunity to provide its fiscal year 2008 recommendations and looks forward to working with the subcommittee in the coming weeks and months.

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#### PREPARED STATEMENT OF THE COALITION FOR INTERNATIONAL EDUCATION

Mr. Chairman and members of the subcommittee: We are pleased to have the opportunity to present the views of the Coalition for International Education on fiscal year 2008 funding for the Higher Education Act, Title VI and the Mutual Educational and Cultural Exchange Act, section 102(b)(6), commonly known as Fulbright-Hays. The Coalition for International Education is an ad hoc group of over 30 national higher education organizations with interest in the Department of Education's international and foreign language education programs. Together the Coalition represents the Nation's 3,300 colleges and universities, and organizations encompassing various academic disciplines, as well as the international exchange and foreign language communities. The urgency about United States shortfalls in international expertise against a backdrop of enormous global challenges is so strong within the higher education community that it draws our different perspectives into a single consensus position.

We express our deep appreciation for the subcommittee's long-time support for these programs. We believe that global challenges to our Nation and its leadership continue to underscore the importance of training specialists in foreign languages, cultures and international business who can offer their skills to the government, the

private sector, educational institutions and the media, and who can communicate across cultures on our behalf.

#### PROGRAM OVERVIEW AND FUNDING HISTORY

In 1958 at the height of the cold war, Congress created these programs out of a sense of crisis about United States ignorance of other countries and cultures. They have served as the lynchpin for producing international specialists for nearly five decades. Expanding over time to meet new global challenges, fourteen Title VI/Fulbright-Hays programs support activities to improve our educational capabilities, from K–12 through the graduate levels and advanced research, with emphasis on the less commonly-taught languages and areas of the world. Title VI largely supports the domestic side of training and research, while Fulbright-Hays supports the overseas component. The programs leverage a large amount of additional non-Federal resources and are relied upon by other Federal and non-Federal programs. Outside resources are essential incentives to develop and sustain these interdisciplinary programs, underwrite high cost programs in the less commonly-taught languages and areas, and provide extensive outreach and collaboration among educational institutions, government agencies, and corporations.

Developing the international expertise the Nation will need in the 21st Century requires educational reform and sustained financing. International expertise cannot be produced quickly. Just as the Federal Government maintains military reserves to be called upon when needed, it should invest steadily in an educational infrastructure that trains sufficient numbers and diversity of American students. Unfortunately, historical under-funding of Title VI and Fulbright-Hays combined with expanding needs and rising costs have contributed to the Nation's shortfall in specialists today. A March 2007 report by the National Research Council concludes: "Title VI/FH funding, including staff resources, has not kept pace with the expansion in the mission of the programs." Funding for key Title VI/Fulbright-Hays programs is more than 30 percent below the high point in fiscal year 1967. For example, only 1,561 or 33 percent fewer Foreign Language and Area Studies fellowships were awarded in fiscal year 2007 compared to 2,344 in fiscal year 1967. Four years of level funding combined with across-the-board cuts since fiscal year 2003 eroded by 10 percent in real terms the fiscal year 2002–2003 funding increases. Our statement today speaks to the urgent need to resume the infusion of new funds into Title VI/Fulbright-Hays, to ensure that this expertise is readily available when needed.

#### WHY INVESTING IN TITLE VI/FULBRIGHT-HAYS IS IMPORTANT

Our national security, stability and economic vitality depend, in part, on American experts who have sophisticated language skills and cultural knowledge about the various areas of the world.

*Government Needs.*—The quantity, level of expertise, and availability of U.S. personnel with high-level expertise in foreign languages, cultures, political, economic and social systems throughout the world do not match our national strategic needs at home or abroad.

—“All of our efforts in Iraq, military and civilian, are handicapped by Americans' lack of language and cultural understanding. Our embassy of 1,000 has 33 Arabic speakers, just six of whom are at the level of fluency. In a conflict that demands effective and efficient communication with Iraqis, we are often at a disadvantage. There are still far too few Arab language—proficient military and civilian officers in Iraq, to the detriment of the U.S. mission.” *The Iraq Study Group: The Way Forward—A New Approach, December 2006.*

—“We have begun the process to imbed language and regional expertise as a core military skill. The need for language and regional expertise has long been a core requirement for Special Forces Command, but as the type of conflicts and wars in which we engage change, and irregular operations and counterinsurgency and stability operations increase, language and regional expertise and cultural awareness become key skills needed by every Soldier, Marine, Sailor, and Airman for this century's global and ever-changing mission.” *David S.C. Chu, Under Secretary of Defense for Personnel and Readiness, before the Senate Armed Services Personnel Subcommittee, March 2006.*

—“It is a mark of how far the FBI still has to go to remake itself into a first-rate counter-terrorism force that 5 years after Sept. 11, 2001, it has only 33 special agents, with one more on the way, who speak Arabic. Most of them don't speak it very well. Only six have a rating of “advanced professional” in the language—one twentieth of 1 percent of the bureau's 12,000 agents.” *Washington Post Editorial, October 2006.*

*Workforce Needs.*—National security is increasingly linked to commerce, and U.S. business is widely engaged around the world with joint ventures, partnerships, and economic linkages that require its employees to have international expertise both at home and abroad.

—“Most of the growth potential for U.S. businesses lies in overseas markets. Already, one in five U.S. manufacturing jobs is tied to exports. In 2004, 58 percent of growth in the earnings of U.S. businesses came from overseas. Foreign consumers, the majority of whom primarily speak languages other than English, represent significant business opportunities for American producers, as the United States is home to less than 5 percent of the world’s population.” *Education for Global Leadership, Committee for Economic Development, 2006.*

—“A study on the internationalization of American business education found that knowledge of other cultures, cross-cultural communications skills, experience in international business, and fluency in a foreign language ranked among the top skills sought by corporations (especially small and mid-size) involved in global business. Despite new efforts to internationalize business education in the last decade, U.S. business schools still fall short of fulfilling the need of businesses for personnel who can think and act in a global context.” *U.S. Business Needs for Employees with International Expertise, Ben L. Kedia and Shirley Daniel, January 2003.*

—The war on terrorism threatens U.S. economic prosperity—and economic stability worldwide—in ways that are not yet entirely understood. Businesses are re-evaluating the risks they face for their employees, their products and services, and their investments in domestic and global markets. The Title VI Centers for International Business Education and Research are mobilizing the intellectual resources of U.S. universities to focus on homeland security and risks in global markets for American business. *See: Homeland Security & U.S. International Competitiveness, CIBERWeb.msu.edu.*

*Improving our Image Abroad.*—More Americans with understanding of other cultures and proficiency in foreign languages helps to improve the Nation’s tarnished image abroad.

—Undersecretary of State for Public Diplomacy and Public Affairs Karen Hughes in an interview with Parade magazine places some of the responsibility for America’s image abroad on the United States. The article states: “She talks about how—before 9/11—people abroad perceived the United States as being uninterested in the rest of the world. Our military, cultural and economic power ‘buy resentment around the world,’ she says. ‘It will take all of us to address that. Any American who travels abroad is an ambassador for our country, and I hope you’ll demonstrate the respect America has for different countries and cultures.’ She’d like more U.S. students to study abroad and more Americans to learn a foreign language.” *Interview with Karen Hughes in PARADE MAGAZINE: “Can the U.S. Rebuild Its Image?” January 28, 2007.*

*Language and Area Training.*—Title VI/Fulbright-Hays programs expand foreign language and area studies enrollments, train K–16 foreign language teachers, and build the training infrastructure in the less commonly-taught languages and areas most needed by the national security agencies, such as Chinese, Russian, Arabic, Korean, Hindi, Urdu, among many others.

—Title VI institutions account for 3 percent of all colleges and universities that offer language instruction, but 21 percent of undergraduate enrollment and 56 percent of graduate enrollment in the less commonly taught languages. For the rare languages, Title VI institutions account for 49 percent of undergraduate and 78 percent of graduate enrollments.

—Title VI institutions provide instruction in roughly over 130 languages and in 19 world areas, and have the capacity to teach over 200 languages. Because of the high cost per student, many of these languages would not be taught on a regular basis at all but for Title VI and Fulbright-Hays support.

—The decline in foreign language enrollments in higher education from 16 percent of total student enrollments in 1960 to just 8.7 percent today must be reversed to meet the increasing demand for globally competent personnel, and to address national needs.

—Only 5 percent of all higher education students taking foreign languages study non-European languages spoken by roughly 85 percent of the world’s population.

—U.S. educational institutions from K–16 face a shortage of teachers with global competence, especially foreign language teachers of the less commonly taught languages. Faculty in professional disciplines require greater international expertise.

## PRESIDENT'S FISCAL YEAR 2008 REQUEST AND THE COALITION'S RESPONSE

The President's fiscal year 2008 budget recommends \$105.75 million for Title VI and Fulbright-Hays. This represents the same level as fiscal year 2006 for these programs. As part of the National Strategic Language Initiative (NSLI), a \$1 million E-learning clearinghouse for critical need languages is proposed at the expense of existing Title VI programs that also serve foreign language needs. The Coalition proposes \$132.6 million for fiscal year 2008. We support the creation of the E-learning clearinghouse only if new funds are made available and a broader spectrum of less commonly taught languages than the administration is recommending is included.

## WHAT ADDITIONAL FUNDING OF \$26.9 MILLION OVER THE REQUEST WOULD ACCOMPLISH

Strengthen foreign language, area and international business education and research: \$114 million for Title VI, Parts A&B—a \$22.5 million increase.

—*Fund an Additional 350 Academic Year and 200 Summer Title VI Foreign Language (FLAS) Fellowships—35 Percent More Than the Request.*—This would restore the number of foreign language academic year fellowships to about 85 percent of the number funded in fiscal year 1967, and 100 percent of the number of summer fellowships funded in that year. Cuts or level funding since fiscal year 2003 have resulted in a cumulative loss of over 340 academic year fellowships in the last 4 years. (\$10.75 million)

—*Increase the Center Grants for the National Resource Centers (NRC), Language Resource Centers (LRCs), and Centers for International Business Education and Research (CIBERs) to Their Fiscal Year 2003 Levels Adjusted for Inflation.*—Cuts, inflation, and an increase in the number of centers in last year's competition have caused a 15–20 percent reduction (adjusted for inflation) in the average grant for these vital centers. This would restore center awards that have eroded over the last 4 years to about 100 percent of their fiscal year 2003 levels in real terms. The additional funding will: (1) accelerate efforts to begin training a new generation of international/language specialists and faculty, especially for the less commonly taught languages, who will be needed to replace those expected to retire over the next decade; (2) expand professional development for teachers of critical languages at both the K–12 and higher education levels, as well as the development of widely accessible critical language teaching materials and assessments for students of critical languages; and (3) step up programs in the critical languages in business education, as well as expand research and education on homeland security and risk management. (\$8.5 million)

—*Sustain and strengthen other Title VI activities, including the undergraduate foreign language and international studies, international research and studies, business and international education programs, American Overseas Research Centers, and information technology innovation.* Additional funds would build and strengthen programs in critical languages, including advanced language training at home and abroad. It would also increase resources for the development of curriculum materials, assessment instruments and research, as well as obtaining from abroad and disseminating educational information about world regions. (\$3.25 million)

Increase the diversity of U.S. students who major in international fields: \$3 million for the Institute for International Public Policy, TVI–C—a \$1.4 million increase. The Institute for International Public Policy responds to the national need for a diverse pool of well-trained, language-proficient professionals to enter the Foreign Service and related careers. The additional funds would raise the number of entering fellows by 50 percent and extend the pipeline to recruit graduate students and those working in international affairs to focus on strategic languages and issues. It also would restore and expand the capacity building grants for minority serving institutions to strengthen foreign language instruction on campus and in local secondary schools, including collaborative efforts with other Title VI grantee institutions.

Strengthen the overseas component of research and training of Americans in foreign languages and international studies: \$15.6 million for Fulbright-Hays—a \$3 million increase. Fulbright-Hays provides an essential overseas component for research and training of Americans in foreign languages and international studies. Overseas immersion is critical to achieving high levels of foreign language proficiency. All of the Fulbright-Hays programs require strengthening, with emphasis on increasing the number of research abroad fellowships and group projects abroad in intermediate and advanced language training in strategic world areas, and expanding curriculum development and summer seminars abroad for K–12 teachers.

## APPROPRIATIONS BILL LANGUAGE

In the last 6 years, Congress has enacted language in the appropriations bill to provide these programs with more flexibility for overseas immersion opportunities for foreign language training, and to permit use of Fulbright-Hays funds, in addition to teaching, in fields including government, professional fields or international development. It also provides a 1 percent set aside for the Department of Education to carry out evaluation, outreach and dissemination activities. The Coalition recommends a continuation of the following language, but with the insert noted in bold to provide the Secretary with more flexibility in using the 1 percent set-aside.

*“Provided further, That notwithstanding any other provision of law, funds made available in this act to carry out title VI of the Higher Education Act of 1965, as amended, and section 102(b)(6) of the Mutual Educational and Cultural Exchange Act of 1961 may be used to support visits and study in foreign countries by individuals who are participating in advanced foreign language training and international studies in areas that are vital to United States national security and who plan to apply their language skills and knowledge of these countries in the fields of government, the professions, or international development: *Provided further, That up to 1 percent of the funds referred to in the preceding proviso may be used for program evaluation, national outreach, and information dissemination activities [insert: that may be carried out by the Secretary or through grants and contracts to institutions of higher education or public and private nonprofit agencies and organizations]*”*

Finally, the Coalition is eager to work with the subcommittee on several recommendations in the just released March 2007 National Research Council’s report on these programs entitled, “International Education and Foreign Languages: Keys to Securing America’s Future.”

We consider our request to be a modest one for programs vital to our Nation’s long-term security and economic well-being. Thank you for your consideration of our views.

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 PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to provide this testimony for the record to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding fiscal year 2008 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors appreciate the subcommittee’s continued support for the LIHEAP program and recognize the difficult challenges facing the subcommittee in this time of severe fiscal constraints. In light of the continuously increasing cost of home energy, the Governors request that Congress provide the authorized level of \$5.1 billion in regular fiscal year 2008 funding as well as contingency funds to address energy emergency situations. Funding at the authorized level will restore some of the program’s purchasing power and also provide States across the country with additional resources to help our most vulnerable citizens afford to heat their homes.

Home energy prices—for heating oil, natural gas, propane and electricity—have dramatically increased in recent years. According to the Energy Information Administration, the average cost for home heating has risen from \$550 during the winter of 2001–2002 to a projected \$862 this year—a 56 percent increase. Low-income households, whose growth in income is far below the rise in energy prices, face the prospect of keeping their homes at unhealthy or unsafe temperatures, using unsafe alternative heating options, or accumulating high levels of home energy debt and the possibility of utility service shut-off. LIHEAP is a vital safety net for the most vulnerable of these low-income households—the elderly and disabled living on fixed incomes, and families with small children. A recent survey by the National Energy Assistance Directors’ Association (NEADA) found that LIHEAP eligible low-income households spent an average of 14 percent of their annual income on residential energy before LIHEAP assistance, but 11 percent after LIHEAP benefits.

The need for home heating assistance far exceeds available Federal and State resources. LIHEAP was able to assist 5.6 million households in fiscal year 2006—the highest level in over a decade, but more than 80 percent of eligible households received no assistance. States across the country in recent years have seen significant increases in their regular LIHEAP caseloads, as well as in requests for emergency crisis from those households in imminent danger of a utility or fuel service cut-off. At the same time, recent price increases have caused the purchasing power of the LIHEAP dollar to plummet, defraying only a modest amount of a low-income household’s total heating bill.

Congress provided much-appreciated additional LIHEAP funds in fiscal year 2006, but most of these funds have already been obligated, will be used for crisis cases this year, or are reserved for cooling assistance for the upcoming summer. As energy prices continue to increase the need for home energy assistance, the reduced LIHEAP Federal funding level in fiscal year 2007 is forcing many States across the country to reduce benefits, limit crisis assistance, or consider closing the program early—even as winter moratoriums on utility shut-off expire this spring.

Without additional Federal resources, the States have limited options to assist these households in need. A continued reduction in benefits could result in limited assistance if recipient households are unable to purchase the required minimum delivery of home heating oil or make the necessary payment on utility arrearages. Many States have used State resources to supplement available LIHEAP funds. Limited opportunities exist to squeeze more assistance dollars from the program, since LIHEAP administrative costs are already among the lowest of human service programs. In order to deliver maximum program dollars to households in need, States in the Northeast have incorporated various strategies to minimize the program's administrative costs including using uniform application forms to determine program eligibility, establishing a one-stop shopping approach for the delivery of LIHEAP and related programs, sharing administrative costs with other programs, and using mail recertification.

In spite of these State efforts to stretch Federal and State LIHEAP dollars, the need for the program is far too great. Increased Federal funding is vital for LIHEAP to assist the Nation's vulnerable, low-income households faced with unaffordable home energy bills. An increase in the regular LIHEAP appropriation to \$5.1 billion for fiscal year 2008 in addition to contingency funds will enable States across the Nation to help mitigate the potential life-threatening emergencies and economic hardship that confront the Nation's most vulnerable citizens. With these additional funds, States can provide assistance to more households in need, offer benefit levels that provide meaningful assistance, lessen the need for emergency crisis relief, plan and operate a more efficient program, and again make optimal use of leveraging and other cost-effective programs.

We thank the subcommittee for this opportunity to share the views of the Coalition of Northeastern Governors, and we stand ready to provide you with any additional information on the importance of the Low Income Home Energy Assistance Program to the Northeast and the Nation.

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## PREPARED STATEMENT OF THE COLLEGE BOARD

### INTRODUCTION

The College Board is a national not-for-profit association of more than 5,000 member schools, colleges, and universities. Its mission is challenging: To connect students to college success and opportunity. One of the College Board's most ambitious and important teaching and learning programs is the Advanced Placement Program (AP). Comprised of 37 college-level courses taught in high school, AP represents the highest standard of academic excellence in our Nation's schools and has become the most influential general education program in the country. A collaborative effort between motivated students, dedicated teachers, expert college professors, and committed high schools, colleges, and universities, the AP Program has allowed millions of students to take college-level courses and exams and to earn college credit or placement while still in high school since its inception in 1955. Ninety percent of the colleges and universities in the United States, as well as colleges and universities in 30 other countries, have an AP policy granting incoming students credit, placement, or both on the basis of their AP Exam grades. Many of these institutions grant up to a full year of college credit (sophomore standing) to students who earn a sufficient number of qualifying AP scores.

President Bush's request for \$122 million in support for AP—including \$90 million in new funding to train AP math, science, and world language teachers—will dramatically improve the quality of instruction in our Nation's schools. The ultimate outcome will be a substantial increase in the number of high school graduates who enter college with the desire and ability to succeed in science, technology, engineering, and mathematics (STEM) fields and compete in a global marketplace. Moreover, increased support for an expanded AP Program will contribute to the goal of raising standards and achievement in all of our Nation's high schools. The AP Program benefits both the students who take AP courses and those who do not take AP by promoting higher standards and better teaching in all classes. As such, a significant

investment in the expansion of AP math, science, and world language programs will have a profound effect on the overall quality of education in our Nation's schools.

#### ADVANCED PLACEMENT PROGRAM

AP is a time-tested program with an existing infrastructure of tens of thousands of teachers and a network of hundreds of training sites across the country. Funds invested in this program will not need to be dedicated to creating a new system for teacher professional development, course development, or the administration and scoring of assessments. That system already exists as a result of our efforts over the past 50 years, and as a result of the involvement of thousands of schools, colleges and universities in the operation of the AP Program. Thus, new Federal dollars invested in AP can go directly into teacher training and student preparation and support.

The principles and values of the AP Program can be stated quite simply:

- AP supports academic excellence. AP represents a commitment to high standards, hard work, and enriched academic experiences for students, teachers, and schools.
- AP is about equity. The AP Program should be open to all students, and we believe that every student should have access to AP courses and should be given the support he or she needs to succeed in these challenging courses.
- AP can drive school-wide academic reform. Schools that use AP as an anchor for setting high standards and raising expectations for all students see significant returns not just in terms of AP participation but in terms of increasing the overall quality and intensity of their academic programs.

Across the Nation, every State, and most school districts are exploring ways to raise standards and ensure that all students take challenging courses that prepare them for success in college and work. AP is recognized as a powerful tool for increasing academic rigor, improving teacher quality, and creating a culture of excellence in high schools. Students who take AP courses assume the intellectual responsibility of thinking for themselves, and they learn how to engage the world critically and analytically—both inside and outside of the classroom. This is an invaluable experience for students as they prepare for college or work upon graduation from high school. Moreover, schools in which AP is widely offered—and accessible to all students—experience the diffusion of higher standards throughout the entire school curriculum.

#### AP MATHEMATICS AND SCIENCE COURSES

Increasing rigorous math and science education in the United States will significantly boost our high school graduates' math and science proficiency, which will increase the number of students who enter college ready to succeed in programs of study leading to science, technology, engineering, and mathematics (STEM) careers. We urgently need to create those opportunities for our students. Today, only 32 percent of American undergraduates earn degrees in science and engineering, compared to 66 percent of undergraduates in Japan, 59 percent in China, and 36 percent in Germany. In 2004, China graduated 600,000 engineers, India graduated 350,000, and the United States graduated 70,000.<sup>1</sup>

The AP Program is an important tool in this Nation's efforts to increase its economic competitiveness. AP math and science students are much more likely than other students to major in STEM disciplines than students whose first exposure to college-level math and science courses is in college. For example:

- Sixteen percent of students who take AP Chemistry go on to major in chemistry in college. By way of contrast, only 3–4 percent of students who take general chemistry instead of AP chemistry major in that field in college.
- More than 25 percent of students who take AP Calculus go on to major in a STEM field in college, and 40 percent of students who take AP Physics major in physics in college.

Furthermore, research indicates that AP math and science courses prepare American students to achieve a level of proficiency that exceeds that of students from all other nations. For example, in the most recent TIMSS assessments, U.S. Calculus students ranked No. 15 (out of 16 countries) in the international advanced mathematics assessment. But AP Calculus students who scored a 3 or better on the AP Calculus Exam ranked first in the world. Even AP Calculus students who scored

<sup>1</sup>Committee on Science, Engineering and Public Policy. *Rising Above the Gathering Storm: Energizing and Employing America for a Brighter Economic Future*. National Academies Press, 2006. This report notes that America appears to be on a "losing path" today with regard to our future competitiveness and standard of living.

a 1 or 2 on the AP Calculus Exam—below “passing”—were ranked second in the world. AP Physics students, as compared to other U.S. physics students and physics students internationally, were also at the top of the ranking.

Most significantly, there are many more U.S. students who could succeed in AP math and science courses—if given the chance. By utilizing an existing, diagnostic tool called AP Potential, more students could be identified as individuals who have the potential to succeed in Advanced Placement classes but may not currently have the opportunity to do so. This year we anticipate that more than 100,000 U.S. students will earn a 3 or above on the AP Calculus Exam—the score typically required for college credit. But in a national analysis of the math proficiency of students enrolled in U.S. high schools during the 2005–2006 academic year, we can identify, by name and school, an additional 500,000 students who have the same academic background and likelihood of success in AP Calculus as the 100,000 students who currently are fortunate enough to have an AP Calculus course available to them.

If we look at Biology, we see an even larger gap; we expect that about 74,000 students will earn exam grades of 3 or higher on the AP Biology Exam this year, whereas we know that at least 640,000 additional U.S. students have the academic skills that would enable them to succeed in AP Biology if they only had a course available to them and the encouragement to take on this challenge. There are hundreds of thousands of high school students in the United States who are prepared and ready to succeed in rigorous high school courses such as AP Calculus, AP Biology, AP Physics, and AP Chemistry. In many cases, the only thing preventing them from learning at this higher level is the lack of an AP teacher in their school or the lack of adequate encouragement and support to take the AP course.

#### CONCLUSION

AP is not for the elite, it is for the prepared. The tremendous potential of AP to drive reform in a powerful way in all of our Nation's schools is well established, and no other program has as strong an impact on overall student and teacher quality as AP. The committee's support for expanded AP math, science, and world language courses and exams will prepare many more students for the opportunity to compete in a global environment and succeed in STEM fields in college and work. We respectfully urge that you fully fund the administration's AP expansion request.

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#### PREPARED STATEMENT OF THE COOLEY'S ANEMIA FOUNDATION

Mr. Chairman and members of the subcommittee: Thank you for the opportunity to present this testimony to the subcommittee today. My name is Frank Somma. I live in Holmdel, New Jersey and I am honored to serve as the National President of the Cooley's Anemia Foundation. As many members of this subcommittee know, Cooley's anemia, or thalassemia, is a fatal genetic blood disorder.

I could bog you down in a detailed scientific explanation of what happens physiologically when the human body cannot produce red blood cells in adequate numbers and of adequate quality to sustain life. I am not going to do that. The important thing for members of this subcommittee to remember about Cooley's anemia is that it is a fatal genetic blood disorder. Period.

I also understand that I can present you with five pages of detailed single-spaced testimony. I am not going to do that either. Instead, I am respectfully going to address the following three issues in a clear and succinct manner.

- The first is the immediate need to retain \$1.94 million in the CDC's Division of Blood Disorders to fund the thalassemia blood safety surveillance network. This program works for thalassemia patients, and for all Americans, by providing a mechanism to take immediate actions to keep the blood supply safe when a threat emerges.
- The second issue is the equally critical need for this subcommittee to commit our government through the NIH—and more specifically through NHLBI—to the development of a vigorous, ethical, progressive and focused gene therapy program that is designed to cure gene disorders in the shortest possible time.
- The third issue is the urgent need to increase funding for the NIH by 6.7 percent a year for the next 3 years to assure the continuation of desperately needed research at NIDDK for the Thalassemia Clinical Research Network at NHLBI.

#### BLOOD SAFETY SURVEILLANCE

Mr. Chairman, when a baby is diagnosed with Cooley's anemia, or thalassemia major, the standard of treatment is to begin that child on blood transfusions. I want to be very clear here that the treatment is not to give the child a blood transfusion;

it is to begin a lifetime treatment regimen of this most invasive and dangerous intervention. Once diagnosed, our patients will receive a blood transfusion every 2 weeks for the rest of their lives.

Because Cooley's anemia patients are transfused so regularly, they represent an "early warning system" for problems in the blood supply. If there is an emerging infection or other problem with the blood supply, it is our patients that will get it first and, because of their fragile health, will likely suffer more greatly from this secondary complications.

Please understand that nearly every patient over the age of 18 today who has thalassemia major also has HIV or hepatitis C as a result of their transfusions—or did have it while they were still alive.

Blood safety is a major national issue. Surgical and trauma patients often have no choice but to be transfused. And, it is done on an emergency basis many times. Nothing is more important to the patient at the time of transfusion than that they can be confident that the blood being pumped into their veins is free from infectious agents—HIV, HCV, or something that none of us have yet heard and doctors have yet to identify.

The blood safety surveillance program is currently operating very effectively through the Division of Blood Disorders in the National Center for Birth Defects and Developmental Disability (NCBDDD) with about \$1.94 million in funding. While the funding is currently in place, this subcommittee and its staff are painfully aware that CDC management attempted to eliminate it following the passage of the fiscal year 2007 Continuing Resolution.

We are respectfully urging that the subcommittee retain this funding at the \$1.94 million level that currently exists in order to continue to protect Americans from unnecessary infections and diseases that may occur in the blood supply. Also, we are requesting that the subcommittee and its staff remain vigilant in protecting this program from unjustified and unjustifiable assaults.

#### GENE THERAPY

Mr. Chairman, as you know, in the last year or 2 we have begun to see evidence of some very good news about gene therapy. After decades of overblown promises and false starts, we can now see a pathway for scientists to follow to help make the promise of gene therapy become the reality of cures. The problem to this point in the long saga that is gene therapy has not been one of science; it has been one of expectations. As a society, we all forgot that science requires trial and error and that experiments are just that—experiments. Sometimes they succeed, but often they fail. And, when they fail, we need to analyze what happened and identify how to correct it . . . and then try again.

Today, gene therapy is advancing at a rapid pace in the rest of the world. Exciting work is being undertaken in Japan and China, in the UK and in France. Unfortunately, it is showing less progress the United States of America . . . and that is not right. We are the international leaders in scientific research and, in a field like this—fraught with financial, scientific and ethical minefields—it is essential that America demonstrate its continued leadership to the world. We set the highest ethical and moral standards on every one of these issues. We protect human subjects best. The future of gene therapy as a means of curing disease is simply too important to leave it to anyone else.

For persons with a single cell mutation disorder like thalassemia or sickle cell disease or severe combined immune deficiency (SCID), gene therapy holds tremendous promise for a cure. In fact, the CAF has recently launched the CURE Campaign: Citizens United for Research Excellence. The theme of the campaign is "It is Time to Cure Something." We are now learning so much about how to deliver healthy genes to unhealthy cells that we cannot turn back—nor can we as a Nation afford to let down the scientists in this country who have such a depth of knowledge and experience. Our friends in Europe and Asia are leaping ahead of us in this critical area of biomedical research and gene therapy.

We hope that this Congress—speaking through this subcommittee—will do what we have done and dare the NIH and its grantees to "cure something." You are investing nearly \$29 billion of taxpayer money in this agency that houses the "best and the brightest" and that funds "the best and the brightest." We as Americans must never stop striving to reach previously unimaginable heights. If that means that we have to shake up the status quo and create a new funding mechanism, let's do it. But let's not continue to follow the slow going incremental, some might say "glacial" path of the past.

We need to spend our tax dollars in a coordinated and focused manner that will maximize the chances that we will unlock the secrets of how to correct single gene

defects. We are gaining direct knowledge of how to safely proceed, with an experiment currently being conducted—in France—that may be a breakthrough. It is time for the United States to step up and lead the world in this life-saving area of research.

#### NIH AND THE THALASSEMIA CLINICAL RESEARCH NETWORK

Mr. Chairman, 6 years ago, working closely with members of this subcommittee from both sides of the aisle, the CAF convinced the NHLBI of the need to create a Thalassemia Clinical Research Network. The purpose of the Network is to create an infrastructure that would enable the top researchers in the field to collaborate on desperately needed research projects using common protocols. Today, the Network is up and running and is the focal point for thalassemia research, most of which takes place in academic medical centers, literally spread from coast to coast.

However, there remains a cloud hanging over this, and all other, research at NIH. As the Biomedical Research and Development Price Index continues to escalate, the buying power of an NIH that has been flat-funded for 4 years continues to decrease. There would be nothing wrong with this if we had cured thalassemia, and hemophilia, and cystic fibrosis, and all other genetic and non-genetic diseases. But that is not the case.

There is an enormous amount of work to be done, treatments to be developed and cures to be found. And there is no one else to do it but our National Institutes of Health, with the support of our Congress and President.

I urge the subcommittee to make a commitment this year in this bill to a 6.7 percent increase per year for NIH for the next 3 years. This level of funding will simply bring us back to where we were in fiscal year 2003 at the end of the 5 year doubling. It is time to commit to undo the damage that has been done in the last 4 years.

#### CONCLUSION

As I indicated at the outset, Mr. Chairman, the Cooley's Anemia Foundation has three priorities this year:

- Funding the blood safety surveillance program at CDC at \$1.94 million;
- An enhanced focus on gene therapy designed to cure something; and,
- A 6.7 percent increase in NIH funding per year for 3 years.

Mr. Chairman, every night when I watch my beautiful, smart, talented 22 year old daughter Alicia suffer from the complications of thalassemia such as osteoporosis and as I watch her endure daily 8–10 hours of painful drug infusions to remove the excess iron in her system from her bi-weekly blood transfusions, I know we can do better than what we are doing now.

Please excuse my passion, but this is the United States of America. I know we can prevent this disease from happening in newborns. I know we can improve the lives of those who currently have it. And, most importantly, I know that we can cure it once and for all.

You don't need four pages of testimony from me to do that. You just need to demand the very best from the very best—our scientists, our government, and ourselves.

Thank you for your very kind attention and for all the support this committee has shown to our patients and their families over the years.

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#### PREPARED STATEMENT OF THE CONSORTIUM OF SOCIAL SCIENCES ASSOCIATIONS

Mr. Chairman and members of the subcommittee, the Consortium of Social Science Associations (COSSA) appreciates and welcomes the opportunity to comment on the fiscal year 2008 appropriations for a number of agencies in the Department of Health and Human Services and the Department of Education. COSSA is an advocacy group promoting attention to and funding for social and behavioral science research. It is supported by more than 110 professional associations, scientific societies, universities, centers and research institutes. A list of our members is attached.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

The mission of AHRQ is to promote health care quality improvement by conducting and supporting health services research that improves the outcomes, quality, access to, cost, and utilization of health care services. As the lead Federal agency charged with supporting research designed to improve healthcare, AHRQ-sponsored research provides evidence-based information that empowers healthcare deci-

sionmakers—patients, clinicians, health system leaders, and policymakers—to make informed decisions that impact the quality of healthcare services delivered.

Health services research also addresses issues of organization, financing, utilization, patient and provider behavior, quality, outcomes, effectiveness, and costs. Since fiscal year 2005, AHRQ has lost nearly \$20 million in purchasing power due flat funding from Congress and inflation. As a member of Friends of AHRQ, COSSA supports the Friends' recommendation for a funding increase of at least \$30 million—just .0015 percent of the \$2 trillion we spent on health care annually.

This funding level would allow AHRQ to support ongoing efforts to improve the quality, safety, outcomes, access to and cost and utilization of health care services. In addition, AHRQ will be able to expand its efforts to improve patient safety, modernize health care through health information technology, develop the next generation of researchers, and evaluate the relative value of alternative technologies.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC is the lead Federal agency for promoting health and safety and providing credible health information through strong partnerships, both nationally and internationally. As the command center for our Nation's public health defense system against emerging and reemerging infectious diseases, the CDC faces unprecedented challenges and responsibilities, ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic. COSSA commends the CDC for acknowledging that as human behavior and demographics create new public health challenges, the expertise within the social and behavioral sciences will be critical in keeping the American public healthy. These behavioral factors—tobacco use, poor diet, physical inactivity, risky sexual behavior and illicit drug use—are, according to the CDC, "the underlying causes for nearly half of all deaths in the United States."

As a member of the CDC Coalition, a nonpartisan coalition of more than 100 groups committed to strengthening our Nation's prevention and health promotion programs, COSSA supports the Coalition's recommendation of a \$10.7 billion appropriation for CDC (including funding for the Agency for Toxic Substances and Disease Registry, and the Vaccines for Children Program). This funding enables the agency to carry out its mission to protect and promote good health and to assure that research findings are translated into effective State and local programs. CDC's programs are crucial to the health of millions of Americans, a key to maintaining a strong public health infrastructure, and essential in protecting us from threats to our health.

The National Center for Health Statistics (NCHS), housed within CDC, provides critical information to guide actions and policies to improve the health of the American people. NCHS data document the health status of the U.S. population and identify disparities in health status and the use of health care by race/ethnicity, socioeconomic status, region, and other population characteristics. New demands for health information exceed the capacity of our current data systems. At few points in recent history has the need for information been greater.

Stagnant and reduced funding throughout most of the last decade has forced significant reduction in some of the NCHS' most important monitoring tools. Since fiscal year 2005, NCHS has lost \$13 million in purchasing power due to a combination of flat funding and inflation. As a result, key NCHS programs are in jeopardy. For example, NCHS lacks resources to collect a full year's worth of vital statistics from States. Without at least \$3 million in additional funding, we will become the first industrialized Nation unable to continuously collect birth, death, and other vital information. Funding shortfalls are also preventing the collection of data on many other key health care issues.

As a member of the Friends of NCHS, COSSA supports the Friends recommendation of a fiscal year 2008 funding level of \$117 million for the agency, an increase of just \$8 million over fiscal year 2007.

#### THE INSTITUTE OF EDUCATION SCIENCES (IES)

Improving the education of our children may be the most widely shared priority in the United States today. Support for other issues may come and go, but recognition of the importance of education and the government's opportunity to improve the state of education in our Nation seems only to grow. Indeed, through No Child Left Behind (NCLB), the President has made education his top domestic priority. Members from both sides of the aisle have offered legislation to reform and improve the educational system. Yet after the legislation passes, what will guide the policies that underlie the education our children receive? Most people, including the current administration, would agree that what should guide education policy is what works

best. We can accomplish finding what works best through impartial, scientific research that evaluates the efficacy of programs in an objective, systematic way and subjects findings to public scrutiny and scientific peer review.

The Education Sciences Reform Act of 2002 reauthorized the Department's educational research, statistics, and assessment activities and placed them in the newly created IES. A cornerstone of the administration's NCLB initiative is investment in research to identify effective instructional and program practices, as well as data collection needed to track student achievement and measure education reform. The new structural and management reforms underway at IES insure that the Federal investment in education research is well managed and relevant to the needs of educators and policymakers.

The \$162.5 million request for research, development, and dissemination would support IES-sponsored education research, development, and dissemination, and the funding of discretionary grants and contracts that support directed and field-initiated research. The request would also include funding for the What Works Clearinghouse, which provides evidence-based information for policymakers, researchers, and educators on promising approaches and interventions, the National Library of Education, and the Education Research Information Clearinghouse (ERIC). COSSA supports increasing this amount to \$180 million. This funding increase would enable IES to continue to support a diverse portfolio of directed and field-initiated research, including its eight national research and development centers. To strengthen the education research enterprise, new opportunities are needed for investigator-initiated studies that move the field forward with innovative methods and research ideas.

The \$29 million increase for the National Center for Education Statistics (NCES), which COSSA strongly supports, would allow it to conduct a pilot study on the development of a postsecondary student level data system that is essential for computing postsecondary completion rates and measuring the true costs of higher education. Funds also would support a new secondary school longitudinal study, scheduled to begin in 2007, which will follow a ninth grade cohort through high school and college.

Assessment is a critical part of the President's education plan No Child Left Behind (NCLB). The fiscal year 2008 budget request includes funding NAEP and the National Assessment Governing Board. The \$23.5 million increase, which COSSA supports, will allow the Department to complete preparations for implementing State-level assessments at the 12th grade level in 2009.

Part of the NCLB mission is closing the achievement gap. To this end, the President's budget would provide awards to enhance States' capacity for accurate reporting of high school graduation and dropout data, and to increase the capability of States to comply with Federal reporting requirements. The Statewide Data Systems program supports competitive awards to State educational agencies to foster the design, development, and implementation of longitudinal data systems that would enable States to use individual student data to enhance the provision of education and close achievement gaps. COSSA supports the proposed increase of \$30 million for this activity in fiscal year 2008.

#### TITLE VI AND FULBRIGHT-HAYS

The importance of knowing about foreign cultures, economies, histories, and politics, and the ability to speak other languages besides English is critical to functioning in today's world. On March 27, the National Academies' released its report: International Education and Foreign Languages: Keys to Securing America's Future. The report concluded that the programs supported by the Department of Education—Title VI and Fulbright-Hays—were successful and useful and indicated that the country was getting internationally educated people at a small cost, because the universities are able to leverage the money from the Education Department. However, the report also proclaims that the funding for the Title VI and Fulbright-Hays programs has not kept up with the expanding pace of their mission as world conditions have changed dramatically.

The historical under-funding of Title VI and Fulbright-Hays combined with expanding needs and rising costs have contributed to the Nation's shortfall in specialists today. As the Coalition for International Education (CIE), of which COSSA is a member, has pointed out funding for key Title VI/Fulbright-Hays programs is more than 30 percent below the high point in fiscal year 1967. For example, only 1,561 or 33 percent fewer Foreign Language and Area Studies fellowships were awarded in fiscal year 2007 compared to 2,344 in fiscal year 1967. Four years of level funding combined with across-the-board cuts since fiscal year 2003 have begun to erode the earlier gains. There is an urgent need to increase funding for these pro-

grams. COSSA supports the CIE's recommendation of a \$132.6 million appropriation for fiscal year 2008.

#### JAVITS FELLOWSHIPS AND THURGOOD MARSHALL LEGAL OPPORTUNITY GRANTS

COSSA supports increasing the funding for the Jacob Javits Fellowship Program, which provides graduate students with the funds to pursue advanced degrees in the social sciences, arts, and humanities. For many years the budget of this program has stagnated and in recent years across-the-board cuts have reduced a rather small budget even further. COSSA recommends funding at \$12 million in fiscal year 2008. Providing student support for those pursuing degrees in these fields is important to the future of this country. America does not compete in a rapidly changing global environment by only supporting physicists and engineers!

COSSA also supports the restoration of funding for the Thurgood Marshall Legal Opportunity Grants to help members of underrepresented groups prepare for a legal education. It is imperative that the legal profession look like the American we have become and are becoming. That means offering opportunities to those who need a leg up to obtain a legal education. COSSA recommends funding at \$3 million in fiscal year 2008.

In conclusion, COSSA acknowledges the subcommittee's history of support for these critical programs that promote health, prevent disease, and help educate a new generation of students. We hope that support will continue in fiscal year 2008.

Thank you for the opportunity to present our views.

#### PREPARED STATEMENT OF THE COPD FOUNDATION

##### AGENCY RECOMMENDATIONS

##### *Department of Labor—Employment and Training Administration*

*Training Demonstration to Employ Disabled Americans.*—The Foundation recommends that the Department provide increased emphasis and support for training disabled Americans. The Chronic Obstructive Pulmonary Disease (COPD) Foundation initiative that trains COPD patients to work on a hotline that provides counseling and health referral information to COPD patients across the country is a project that uses technology based training, helps SSI and SDI recipients find employment, and helps meet documented job market demand. The Foundation urges favorable consideration of this and similar initiatives to train disabled Americans.

##### *Center for Disease Control and Prevention—National Center for Chronic Disease Prevention*

*COPD Self Management Demonstration.*—Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death and is a chronic condition similar to diabetes that requires an aggressive self-management in order to prevent continued deterioration, hospitalization, and costly medical interventions. In view of the increasing mortality, morbidity, and cost to the Nation's health care system, the Foundation urges CDC to demonstrate and validate intervention and training protocols that are needed to improve health outcomes and reduce health care costs for COPD patients. The Foundation urges CDC to work with leading health care organizations to develop and validate self management protocols.

##### *Center for Disease Control and Prevention—National Center for Public Health Informatics*

*Increasing Awareness, Early Diagnoses, and Treatment for COPD.*—The National Institutes of Health launched an information campaign in January, 2007 designed to increase awareness, diagnoses, and treatment for Chronic Obstructive Pulmonary Disease (COPD). COPD is a growing epidemic, the fourth leading cause of U.S. deaths, and affects 1 in 4 Americans over the age of 45. More than 12 million people are currently diagnosed with COPD and it is estimated that another 12 million have it but remain undiagnosed despite recognizable symptoms and treatments that can control symptoms and prolong life. CDC is urged to collaborate with leading COPD health care organizations to support the effort to increase public awareness, early diagnosis, and treatment for COPD.

##### *National Institutes of Health—National Heart, Lung, and Blood Institute—Division of Lung Diseases*

*Chronic Obstruction Pulmonary Disease.*—Chronic Obstructive Pulmonary Disease (COPD) is a growing epidemic, the fourth leading cause of U.S. deaths, and affects one in four Americans over the age of 45. In view of these trends, it is noted that only 10 percent of the Division of Lung Disease research portfolio is focused on

COPD. The Foundation commends the Division of Lung Diseases for sponsoring several COPD workshops that have recommended additional research focused on the disease process, pathogenesis, and therapy and other recommendations. The Foundation recommends that the NHLBI aggressively pursue COPD research as recommended by these expert panels and convene a panel of leading researchers from across the country to create a COPD Research Action Plan to identify opportunities and to accelerate the pace of research.

Mr. Chairman and members of the subcommittee thank you for the opportunity to submit testimony for the record on behalf of the COPD Foundation.

#### THE COPD FOUNDATION

Established in 2004, the COPD Foundation has a clear mission: to develop and support programs, which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease. Chronic obstructive pulmonary disease (COPD) is an umbrella term for a group of lung disorders that result in obstruction to airflow in the lung causing breathlessness. The four diseases classified under COPD are emphysema, chronic bronchitis, refractory asthma, and severe bronchiectasis. The COPD Foundation was established to speed innovations which will make treatments more effective and affordable. It also undertakes initiatives that result in expanded services for COPD patients and improves the lives of patients with COPD through research and education that will lead to prevention and someday a cure for this disease.

The COPD Foundation is led by a diverse Board of Directors that includes patients with COPD, as well as some of the most recognized professionals involved in COPD clinical practice, research and patient care. Under the board's direction, the COPD Foundation has established policies based on industry best practices from the Better Business Bureau's Wise Giving Alliance and the National Health Council in areas of governance, accountability and transparency. The first of the COPD Foundation's research initiatives is a partnership with the Scarborough family for the Richard H. Scarborough Bronchiectasis Research Fund, aimed to support translational research to halt or reverse the airways destruction of bronchiectasis.

#### COPD: FOURTH LEADING CAUSE OF DEATH AND RISING

Chronic Obstructive Pulmonary Disease (COPD) was the fourth leading cause of death in 2003 based on the Centers for Disease Control and Prevention's final data, which attributes 126,382 deaths to COPD for the year. Given that figure, a person dies of COPD every 4 minutes, and because of the mechanisms of this devastating disease, he or she slowly suffocates to death over several years as airway obstruction and breathlessness increase. No one knows exactly how many people in the United States have this terrible disease, but estimates range from 12 million diagnosed with another 12 million symptomatic, undiagnosed and at risk.

The decreased ability to breathe causes severe physical and mental disability in afflicted individuals. In a 2004 survey, over 50 percent of patients said that their disease limited the amount or type of work they were able to do, and of those patients nearly 80 percent were unable to work at all due to their breathlessness. Many of these individuals would otherwise have the ability to continue working for many years.

COPD cost the U.S. economy \$32 billion in 2002 and it is estimated that 600 million people worldwide have the disease.

#### THE MEDICAL NEEDS OF THE COPD COMMUNITY HAVE GONE UNMET

While smoking is a predominant cause of COPD it is not the only cause. Other significant factors are second hand smoke, occupational dusts and chemicals, air pollution, and a genetic cause called alpha-1 antitrypsin deficiency.

The other leading causes of death have seen great improvements over the past several decades. While the mortality of COPD rose by 163 percent from 1965-1998, the mortality of coronary heart disease decreased by 59 percent and the mortality of stroke decreased by 64 percent.

Yet this fourth leading cause of death is a hidden, silent killer. There is a lack of awareness among the public that coughing and breathlessness is not a normal sign of aging. Those diagnosed with this disease are quick to blame themselves and are ashamed of their disease because of the current societal stigma. Many lack the information for proper disease self-management, which could easily prevent exacerbations and thusly, many hospital and emergency room visits.

Currently, the only therapy shown to improve survival is supplemental oxygen. There are other therapies that can improve symptoms but they do not alter the natural history of the disease.

#### DETECTION

COPD is fairly easy to detect: in addition to symptoms of breathlessness, cough and sputum production, spirometry is a quantitative test that measures air volume and air flow in the lung and is relatively easy and inexpensive to administer.

#### COPD RESEARCH

The COPD Foundation believes that significant Federal investment in medical research is critical to improving the health of the American people and specifically those affected with COPD. The support of this subcommittee has made a substantial difference in improving the public's health and well-being. While this is by no means an exhaustive list, the Foundation wishes to recognize and appreciate the efforts of the National Institutes of Health in creating the COPD Clinical Research Network, for conducting a COPD state of the science conference, and commends NHLBI for the national launch of the COPD Awareness and Education Campaign titled "COPD Learn More Breathe Better".

Chronic diseases have a profound human and economic toll on our Nation. Nearly 125 million Americans today are living with some form of chronic condition. The Foundation recognizes that the Centers for Disease Control and Prevention understands that COPD is one of the only top 10 causes of death that is on the increase, however, COPD has not been designated the resources to be a major focus of the CDC. The Foundation urges the subcommittee to encourage the CDC to expand its data collection efforts and to expand programs aimed at education and prevention of the general public and health care providers.

NIH and CDC: The Foundation requests that the National Institutes of Health in fiscal year 2008 receive an increase of 6.7 percent over fiscal year 2007 Joint Resolution Funding Levels. The COPD Foundation joins the Ad Hoc Group for Medical Research Funding, a coalition of some 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry in making this recommendation. The fiscal year 2008 administration budget request for NIH is a \$511 million cut (1.7 percent) below the final fiscal year 2007 levels. If implemented, this funding level would mean NIH's ability to conduct and support life-saving research will be cut by more than 13 percent in inflation-adjusted dollars since fiscal year 2003. The NIH, National Heart Lung, and Blood Institute, National Institute of Allergy and Infectious Diseases and National Institute on Aging, should increase the investment in Chronic Obstructive Pulmonary Disease and the Centers for Disease Control and Prevention should initiate a Federal partnership with the COPD community to achieve the following goals:

- Promotion of basic science and clinical research related to COPD;
- Programs to attract and train the best young clinicians for the care of individuals with COPD;
- Support for outstanding established scientists to work on problems within the field of COPD research;
- Development of effective new therapies to prevent progression of the disease and control symptoms of COPD;
- Expansion of public awareness and targeted detection to promote early diagnosis and treatment.

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#### PREPARED STATEMENT OF THE CORPS NETWORK

The Corps Network (formerly the National Association of Service and Conservation Corps or NASCC) appreciates the opportunity to submit testimony to the subcommittee about the critical need for funding AmeriCorps and other national service programs in fiscal year 2008.

We urge you to make much needed, and long overdue, investments in AmeriCorps and other national service programs supported by the Corporation for National and Community Service (CNCS).

Specifically, we recommend that the subcommittee fund:

- AmeriCorps State and National Grants at \$312 million;
- The National Service Trust at \$143 million;
- The National Civilian Community Corps (NCCC) at \$26.7 million; and
- AmeriCorps VISTA at \$95 million.

We believe that these funding levels would adequately support 75,000 AmeriCorps members and retain the historic balance between full- and part-time service.

Established in 1985, The Corps Network is the voice of the Nation's 113 Service and Conservation Corps. Currently operating in 41 States and the District of Columbia, Corps annually enroll more than 23,000 young men and women who contribute 13 million hours of service every year. Corps annually mobilize approximately 125,000 community volunteers who contributed more than 2.4 million additional hours of service.

Service and Conservation Corps are a direct descendent of the Civilian Conservation Corps (CCC) that built parks and other public facilities still in use today. Like the legendary CCC of the 1930s, today's Corps are a proven strategy for giving young men and women the chance to change their communities, their own lives and those of their families. Service and Conservation Corps provide a wealth of valuable conservation, infrastructure improvement and human service projects. Some Corps tutor and some fight forest fires. Others complete a wide range of projects on public lands. Still others improve the quality of life in low-income communities by renovating deteriorated housing, engaging in environmental restoration, creating parks and gardens and staffing after-school programs.

Service and Conservation Corps serve young people who are most in need. Since 1985, approximately 600,000 young people have completed service in our Nation's Service and Conservation Corps. Approximately 57 percent of our Corpsmembers are young people of color, 64 percent come from families with income below the poverty line, at least 30 percent have had previous court involvement and at least 10 percent have been in foster care. More than half of all Corpsmembers enroll without a high school diploma.

Today's Corps are a proven strategy for giving young men and women, many of whom are economically or otherwise disadvantaged and out-of-work or out-of-school, the chance to change their own lives and those of their families, as well as improve their communities. Corps represent the country's largest full-time, non-federal system for youth development.

I would like to share with you three examples of why AmeriCorps funds are so important to our Nation. The Corps Network administers three AmeriCorps programs, the Gulf Coast Recovery Corps, the Civic Justice Corps and RuralResponse that address important societal problems through service.

The AmeriCorps Gulf Coast Recovery Corps:

- Assists residents impacted by the devastation of Hurricane Katrina and Rita in the long-term recovery efforts along the Gulf Coast of Mississippi.
- Deploys crews of young people (ages 18–25) from the Nation's 113 Service and Conservation Corps for 4-week projects that include rebuilding homes and structures, chopping down damaged trees near homes, removing debris, restoring trails, replanting marsh grass and trees, performing environmental restoration and other projects.
- Brings a total of 300 trained and semi-skilled volunteers to the region through the summer of 2007.
- Partners with the Hancock County Long-Term Recovery Committee, Mississippi Commission for Volunteer Service, St. Rose Delima Catholic Church in Bay St. Louis, Mississippi State Parks, U.S. Fish and Wildlife Service and other local and national organizations working in the region.
- Builds on the tradition of Corps helping communities recover from natural disasters, including the San Francisco earthquake in 1989, Hurricane Andrew in 1992, the Mississippi River floods in 1993 and the aftermath of other major hurricanes, floods, tornadoes, and wildfires.
- Will pave the way for a permanent Mississippi Corps, funded in part by the Mississippi Commission for Volunteer Service, to engage local young people in the recovery efforts.
- Is funded by the Corporation for National and Community Service's Federal AmeriCorps program.

The Civic Justice Corps (funded by AmeriCorps and the Department of Labor):

- Re-engages court-involved youth and young adults, not less than 50 percent who have been incarcerated, in their communities, the workforce, education and society as a whole, with the goal of reducing recidivism by at least 20 percent.
- Empowers Corpsmembers through a variety of service projects that meet critical community needs.
- Creates a support system that begins in the corrections facility, continues through the time in the Corps and extends 12 months after the Corps experience.
- Formalizes effective working relationships with justice agencies, employers and other partners.

- Enables Corpsmembers to earn a high school diploma or GED while preparing for careers in high-growth industries or opportunities in post-secondary education.
  - Draws on the experience of Corps which enroll nearly 5,000 court-involved youth each year.
  - Represents a partnership between the Cascade Center for Community Governance, the Open Society Institute, the JEHT Foundation and The Corps Network.
  - Is funded by AmeriCorps in the following sites: Bend, OR; Charleston, SC; Washington, DC.
  - Is funded by the U.S. Department of Labor in the following sites: Austin, TX; Camden, NJ; Denver, CO; Fremont, OH; Fresno, CA; Madison, WI; Miami, FL; Oakland, CA; Sacramento, CA; San Diego, CA and Wheaton, MD.
- The RuralResponse AmeriCorps Program:
- Enables Service and Conservation Corps to bolster homeland security and disaster response capacity in underserved rural communities by filling gaps in rural emergency response networks.
  - Engages young people (ages 16–25) each year in disaster response as well as traditional service and conservation projects to meet the needs of rural communities.
  - Trains Corpsmembers in specific disaster preparedness and response activities such as first aid, adult and child CPR, mass care, use of global positioning systems (GPS), shelter operations, hazardous materials removal, chain saw safety and use and wildfire suppression.
  - Prepares Service and Conservation Corps for long-term engagement with existing disaster response and preparedness efforts in rural communities.
  - Provides a minimum wage based living allowance and an AmeriCorps Education Award (scholarship) of up to \$4,725 per Corpsmember.
  - Requires a 33 percent non-federal match by Service and Conservation Corps.
  - Is funded by AmeriCorps at \$3.6 million over 3 years in the following sites: Minnesota Conservation Corps, Quilter Civilian Conservation Corps (Fremont, OH), Vermont Youth Conservation Corps and Youth Conservation Corps, Inc. (Waukegan, IL).
- Our work in the Gulf Coast Recovery Corps, the Civic Justice Corps and Rural Response embodies many of AmeriCorps' core principles including:
- Using service in creative ways to meet needs that would otherwise go unmet;
  - Relying on public-private partnerships and using public dollars to attract private funds;
  - A bottom-up structure in which the local community determines the projects on which we work;
  - Communities demonstrate their support for projects by helping Corps meet AmeriCorps' matching requirements;
  - Partnering with local government, State, and Federal land management agencies and local nonprofit organizations, including faith-based groups;
  - Providing an opportunity for all Americans to serve and reconnecting disconnected youth to their communities by insuring that Corpsmembers learn life skills and job skills that enhance their employability; and
  - Using the AmeriCorps Education Award to make higher education accessible to thousands of young people for whom it would otherwise be too costly.
- While it is difficult to describe the “typical” Corps, successful Corps share common core elements. They:
- Rely on a model in which adult leaders serve as mentors, role models, technical trainers and supervisors for crews of 8–12 Corpsmembers;
  - Provide Corpsmembers with a minimum-wage based living allowance;
  - Offer classroom training to improve basic competencies, a chance to earn a GED or high school diploma, experiential and environmental service-learning-based education, generic and technical skills training, a wide range of support services, and, in many cases, an AmeriCorps post-service educational award of up to \$4,725.
  - Build on Corpsmembers' strengths to provide an environment in which every Corpsmember can experience success. They offer consistent contact with a caring adult, stress leadership development, creative problem-solving, and the ability to work as a member of a team; and
  - Provide Corpsmembers a “second chance” to succeed in life and focus youth on the future.
- A 1997 Abt Associates/Brandeis University random assignment study concluded that Youth Service and Conservation Corps are an invaluable resource for young people. According to the study, Corps generate a positive return on investment and

the youth involved were positively affected by joining a Corps. The report documents that:

- Significant employment and earnings accrue to young people who join a Corps;
- Positive outcomes are particularly striking for African-American men;
- Arrest rates drop by one third among all Corpsmembers; and
- Out-of-wedlock pregnancy rates drop among female Corpsmembers.

Abt Associates documents several factors to which the effectiveness of Corps is attributed including:

- Comprehensiveness of services;
- Supportive and dedicated program staff;
- Quality of the service projects;
- Intensity of the service experience; and
- Corpsmembers have access to an expanded social network.

It is critical for CNCS to have sufficient resources to ensure that participants in national service programs are able to continue their crucial work. Restoring our investment in AmeriCorps State and National, the National Service Trust, AmeriCorps\*NCCC and AmeriCorps\*VISTA, will allow more Americans of all ages and backgrounds to serve and create greater capacity to meet critical community needs.

Thank you for your consideration of these requests. If you have any questions, please do not hesitate to contact me at (202) 737-6272 or at [sprouty@corpsnetwork.org](mailto:sprouty@corpsnetwork.org).

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PREPARED STATEMENT OF THE COUNCIL OF STATE AND TERRITORIAL  
EPIDEMIOLOGISTS

PUBLIC HEALTH WORKFORCE: INCREASING STATE AND LOCAL EPIDEMIOLOGY AND  
LABORATORY CAPACITY

*Recommendations*

- \$5 million for the Office of Workforce and Career Development to support 65 CDC/Council of State and Territorial Epidemiology (CSTE) first year applied epidemiology fellows.
- \$2 million increase for the National Center for Infectious Diseases to support 35 CDC/Association of Public Health Laboratories (APHL) applied research training fellows.

Building a strong public health infrastructure, particularly a trained public health workforce with sufficient epidemiologists and public health laboratory scientists—core public health professionals, will take a sustained commitment of resources over a long period of time.

The disciplines of epidemiology and laboratory science are the pillars of public health practice. States and local communities have come to rely on public health epidemiologists and laboratory scientists to investigate, monitor, and respond aggressively to public health threats. Every State's residents have become familiar with the "disease detectives" who communicate risks and provide preventive recommendations during incidents such as the recent outbreak of E. coli in spinach, seasonal influenza, West Nile virus, and epidemics of obesity, diabetes, HIV/AIDS and a host of other serious threats the public has experienced during recent years. The 2006 CSTE National Assessment of Epidemiologic Capacity shows the number and the level of training of epidemiologists is perceived as seriously deficient in most States. Federal funding has increased the number of epidemiologists engaged in bioterrorism preparedness since 2002, but has done so at the expense of State environmental health, injury and occupational health activities—shifting epidemiologists from these activities to Federal bioterrorism preparedness priorities. Those engaged in chronic disease activities have increased since 2002, but are still viewed as too low in number and training. According to the 2003 Institute Of Medicine report, Microbial Threats to Health: Emergence, Detection, and Response, rebuilding domestic public health capacity was among its highest recommendations for addressing both diseases occurring naturally and intentional release of microbial agents.

Efforts under the leadership of CDC have been made to begin addressing these gaps. CDC is supporting training fellowship programs for epidemiologists and laboratory scientists who are expected to increase State capacity and provide future leadership in these professions. CSTE applauds these efforts and proposes aggressive expansion of existing state-focused programs to increase the number of epidemiologists and public health laboratory scientists at State and local health departments. The proposed fiscal year 2008 increase will provide CSTE and APHL with

the resources to accelerate much needed expansion of the State and local workforce in these critical disciplines.

States and localities will benefit through increased numbers of highly trained epidemiologists and laboratory scientists entering employment through training programs that include the following characteristics:

- national recruiting through a partnership between CSTE and the Association of Schools of Public Health;
- orientation and training course with CDC, CSTE, and APHL faculty;
- applicant pool for State and local positions with adequate time to evaluate job performance;
- a structured, individualized training curriculum for each fellow; and
- technical and administrative support for fellows and State mentors.

The capacity and leadership legacy of these state-based programs is intended to be modeled on the success of the Epidemic Intelligence Service and provide States and localities with epidemiology and laboratory leadership for the future.

#### STRENGTHENING CAPACITY IN FOUR CRITICAL PUBLIC HEALTH PROGRAM AREAS

##### *Preparing for an Influenza Pandemic*

Fiscal year 2006 State and Local pandemic influenza preparedness funding is being used to: (1) create and implement, including exercising, emergency pandemic plans; (2) conduct integrated disease surveillance; (3) fund laboratory testing of influenza strains; (4) inform the public; (5) manage distribution of vaccine and antiviral medications; (6) plan for alternative facilities in the event of hospital capacity excess; (7) track vaccine and antiviral use; (8) document adverse outcomes from influenza-related medications. Continued funding at the level of \$250 million in fiscal year 2008 will support these activities and help ensure that our health system is ready for the seasonal influenza epidemics and a potentially catastrophic influenza pandemic.

##### *Epidemiologic-Laboratory Capacity (ELC Cooperative Grant Program)*

CSTE strongly supports a \$53 million increase for the Epidemiologic-Laboratory Capacity program at the CDC for fiscal year 2008. This increase will be instrumental in implementing the CDC plan Preventing Emerging Infectious Diseases: A Strategy for the 21st Century. This program, which supports health departments in 50 States and 6 highly populated cities/counties, was developed to repair the deteriorated surveillance and response capacity for emerging infectious diseases in health departments nationwide. Funds build capability to detect, diagnose, and prevent diseases caused by food, water and vector borne infections, vaccine preventable disease, and drug resistant infections. The early detection and prompt response to West Nile virus (WNV) in 2000 can be attributed to the foundations laid by this cooperative grant program. Funding reductions, beginning in 1998, have compromised the mission of this program and may contribute to a weakened ability to detect and respond to future disease threats. CSTE is very disappointed that the President's fiscal year 2008 budget cuts WNV funding by 45 percent. In an effort to maintain and build public health capacity, CSTE supports full funding (\$110 million) for the ELC cooperative grant program in fiscal year 2008.

##### *Terrorism Preparedness*

State and Local CDC Terrorism Preparedness Grants are used to fortify health department ability to detect and investigate disease occurrence, evaluate infectious outbreaks, and rapidly access, exchange and disseminate relevant information. Funding also provides surge capacity for personnel and supplies that will be needed in the event of a terrorist attack. In fiscal year 2006, funding was cut by \$100 million and remained at that level for fiscal year 2007. The President's fiscal year 2008 budget cuts funding further by \$125 million. While health departments nationwide have made good progress in emergency preparedness, these funding cuts have led to a decreased epidemiology and laboratory capacity due to downsized personnel that were paid with these funds. Further staff reduction, and concomitant reduction in surveillance performed, will leave our Nation's public health system unable to provide bioterrorism threat surveillance and response. CSTE recommends full funding at the fiscal year 2005 level—\$919.1 million.

##### *Preventive Health—Health Services (PHHS) Block Grant*

CSTE is disappointed that the President's fiscal year 2008 budget, once again, eliminates all funding for the PHHS Block Grant and urges restoration of funding to the fiscal year 2005 level of \$131 million. This grant program was developed to allow States flexible use of funds to support objectives identified at the local level. For example, a city with increasing incidence of whooping cough (*Bordetella per-*

tussis) would be able to use funds to intensively track cases and prevent spread of the disease. Other cities or States may use funds to address their region-specific disease trends, such as injection drug related morbidity, sexually transmitted disease, mother-to-child diseases, or hantavirus. Because of the variation in disease prevalence across our diverse Nation, flexible funding with local allocation capacity is necessary to achieve detection, prevention, and community outreach tasks for Americans. CSTE recommends restoration of the PHHS block grant to \$131 million to limit the extent of local disease epidemics spreading to becoming national disease threats.

#### SURVEILLANCE ISSUES: FIVE CSTE PRIORITIES

Epidemiologists working in public health agencies are responsible for monitoring trends in health and health problems, and devising prevention programs that support healthy communities. Surveillance is the foundation for developing a public health response to any disease threat—be it infectious, chronic, environmental, occupational, or injury. Surveillance is useful in (1) determining which segments of the population are at highest risk; (2) identifying changes in disease incidence rates; (3) determining modes of transmission; and (4) planning and evaluating disease prevention and control programs. For fiscal year 2008, CSTE urges Congress to provide the following increased resources for expanding surveillance of key diseases, injury and environmental health areas:

*Behavioral Risk Factor Surveillance Survey (BRFSS).*—Administered by CDC's Center for Chronic Disease Prevention, Health Promotion, and Genomics, the BRFSS is a primary source of information used to guide intervention, policy decisions, and budget direction at the local, State, and Federal level for multiple health conditions and chronic diseases. An increase in funding by \$10 million, to \$18 million, is needed to fully implement the survey. BRFSS is the primary source of information for leading health indicators for 6 areas in Health People 2010. As our Nation moves towards evidence based medicine and funding, our data source needs to be comprehensive enough to accurately reflect the health of our population. Further congressional support will improve data collection infrastructure, timely reporting, and sophisticated analysis to provide data in meaningful ways to end users nationwide.

*HIV/AIDS Surveillance.*—Cooperative Agreement funding to State and Local health departments for HIV/AIDS surveillance is critical to prevent new HIV infections, thereby saving an estimated \$195,000 in lifetime treatment costs per individual. HIV/AIDS incidence is increasing without commensurate increases in Federal spending for surveillance. CSTE urges an increase of \$35 million, to \$101.3 million, for the surveillance cooperative agreements in CDC's HIV/AIDS Prevention budget (total recommendation \$1,049.2 million) to address increasing HIV/AIDS incidence.

*National Violent Death Reporting System (NVDRS).*—Fifty thousand deaths per year in the United States are attributable to violence. The National Center for Injury Prevention and Control (NCIPC) has developed the NVDRS to collect data related to these deaths for use in development of targeted prevention and early intervention programs. Seventeen States currently are equipped with NVDRS, however increased funding will help distribute the program and personnel to all States and strengthen our Nation's ability to collect the data that will ultimately result in reduction in violent deaths. CSTE urges an increase in funding from \$3.4 million to \$10 million for NVDRS, administered by CDC's NCIPC (total \$168 fiscal year 2008 request).

*Occupational Safety and Health State-Based Surveillance (NIOSH Program Announcement PAR 04-106).*—In fiscal year 2005 NIOSH funded 12 States to establish Occupational Safety and Health programs that use 13 occupational health indicators to measure the burden of workplace injury and illness and make recommendations for prevention. This successful program should be expanded to all 50 States to establish a nationwide system to prevent major injuries and illnesses caused by hazardous work conditions. An increase in funding to \$12.5 million, within the \$300 million NIOSH budget request, will allow the expansion of this occupational surveillance to all States.

*Environmental Health Tracking Grants.*—There is no national surveillance system to investigate possible links between environmental exposures and a number of diseases and health conditions, as noted in the PEW Environmental Health Commission's report, *America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*. Most States have little capacity for tracking environmental health. Since fiscal year 2002, Congress has recognized the need for increased environmental health capacity with funding, however a significant increase

is needed to ensure that all States have the ability to track disease occurrence and adverse health conditions and their possible linkages to environmental toxins and hazards (such as the link between asbestos and mesothelioma). Funding at the \$100 million level will strengthen our nations resolve to identify harmful environmental exposures and eliminate the disease burden caused by them.

#### PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation, and the 30,000 people with cystic fibrosis (CF), I am pleased to submit the following testimony regarding fiscal year 2008 appropriations for cystic fibrosis-related research at the National Institutes of Health (NIH) and other agencies.

#### ABOUT CYSTIC FIBROSIS

Cystic fibrosis is a life-threatening genetic disease for which there is currently no cure. People with CF have two copies of a defective gene that causes the body to produce abnormally thick, sticky mucus, which clogs the lungs and result in fatal lung infections. The thick mucus in those with CF also obstructs the pancreas, causing patients difficulty in absorbing nutrients in food.

The common symptoms of CF include chronic cough, wheezing or shortness of breath, excessive appetite but poor weight gain, and greasy, bulky stools. CF symptoms vary from patient to patient, due to the fact that there are more than 1,000 mutations of the CF gene.

Since its founding, the Cystic Fibrosis Foundation has maintained its focus on promoting research and improving treatments for CF. CF has been significantly transformed from a childhood death sentence into a chronic disease, which requires a rigorous daily regimen of therapy. Treatments for individuals with CF include enzymes that aid digestion, antibiotics to treat lung infections, and daily therapy to loosen the mucus in the lungs. Strict adherence to CF treatments improves the health status and quality of life for those with CF, but the regimen can be a daily challenge for patients and their families.

Through the research leadership of the Cystic Fibrosis Foundation, the life expectancy of individuals with CF has been boosted from less than 6 years in 1955 to nearly 37 years in 2005. Today, 43 percent of people with CF are 18 or older. This improvement in the life expectancy for those with CF can be attributed to research advances, which I will discuss in some detail later, and to the teams of CF caregivers who offer specialized care of the highest quality. This improvement in life expectancy is important, but we continue to lose young lives to this disease. Our progress is not nearly sufficient for those living with CF and their families, friends, and caregivers.

The promise for those with CF is in research. In the past 5 years, the Cystic Fibrosis Foundation has invested over \$595 million in its medical programs of drug discovery, drug development, research, care and drug delivery aimed at life-sustaining treatments and a cure for cystic fibrosis. But a greater investment is necessary to accelerate the pace of discovery of CF therapies. This statement focuses on the investment that will be required to develop new CF treatments rapidly and efficiently and to encourage research on a cure.

#### SUSTAINING THE FEDERAL INVESTMENT IN BIOMEDICAL RESEARCH

This subcommittee and Congress are to be commended for their steadfast support for biomedical research, and their commitment to the National Institutes of Health (NIH), including the effort to double the NIH budget between fiscal year 1999 and fiscal year 2003. This impressive increase in funding resulted in a revolution in medical research, fueling discoveries that benefit all Americans.

However, we risk losing the research momentum the doubling generated if we fail to adequately fund the NIH so that they can capitalize on scientific advances. The Cystic Fibrosis Foundation joins the Ad Hoc Group for Medical Research to recommend increasing the NIH budget by at least 6.7 percent in fiscal year 2008. This investment will help maintain the NIH's ability to fund essential biomedical research today that will provide tomorrow's care and cures.

#### STRENGTHENING OUR RESEARCH INFRASTRUCTURE

It is now vital to assess our ability to translate the basic research advances of the last decade into treatment advances. The Cystic Fibrosis Foundation has been recognized for its own research approach to encompass many types of research, from basic research through Phase III clinical trials, and has created the infrastructure

required to accelerate the development of new CF therapies. As a result, we now have a pipeline of more than 25 potential therapies that are being examined to treat people with CF. Several drugs in this pipeline treat the basic defect of CF, while others attack the symptoms of the disease.

The NIH Roadmap for Medical Research provides the opportunity for the NIH to translate research into treatments for people with disease. We applaud Congress for its leadership and support for the NIH's Roadmap, which mirrors the Cystic Fibrosis Foundation's own approach to support and rewards innovation throughout the research process.

Cystic fibrosis is a disease which impacts multiple systems in the body, and as a result, several different institutes at NIH share responsibility for CF research. Having multiple responsible institutes presents roadblocks to CF research in that there can be imperfect communication among the institutes regarding research in the field. This can limit our ability to capitalize on all research opportunities. Moreover, multidisciplinary research approaches, of the sort we believe are most promising in CF, may be disadvantaged in the NIH system of review and funding.

The Cystic Fibrosis Foundation applauds NIH leaders for encouraging multidisciplinary research and Congress for directing resources to the Common Fund to finance multidisciplinary research projects. Funding pioneering multidisciplinary research is critical, but the Common Fund is also important in intangible ways, such as encouraging communication among researchers, placing a high value on trans-institute research, and breaking down barriers to communication and collaboration between institutes. We urge sufficient funding for such a multidisciplinary approach, which is most responsive to the research needs of complex diseases like CF.

#### FACILITATING CLINICAL RESEARCH

The Cystic Fibrosis Foundation applauds the efforts of NIH to encourage greater efficiency in clinical research. The Foundation has been a pioneer in creating a clinical trials network to achieve greater efficiency in clinical investigation. Our pioneering effort in clinical trials emerged from the necessity of a small patient population for the number of trials we are undertaking and because our patients literally cannot tolerate research delays. Yet we believe that our model should be adopted and adapted by others. We have a permanent network of clinical trial sites and have centralized and coordinated data management and analysis functions and data safety monitoring. Among the results of this outstanding network—called the Therapeutics Development Network—are the ability to achieve rapid accrual to trials and the ability to conduct multiple trials simultaneously, even in a population of 30,000 CF patients. Since the TDN's inception, it has conducted over 40 trials. Of course, the ultimate goal of a centralized clinical trials system is the acceleration of the therapeutic development process.

Although we have achieved significant efficiencies in our clinical trials system, we still encounter substantial slowdowns in the review of our multi-institutional trials by the institutional review boards (IRBs) of each of the institutions participating in the trials. We encourage Congress to urge the Department of Health and Human Services to demonstrate more aggressive leadership in persuading academic institutions to accept review by a central IRB—without insisting on parallel and often duplicative review by their own IRB—at least in the case of multi-institutional trials in rare diseases.

#### *Pursuing New Therapies: The Cystic Fibrosis Therapeutics Development Network*

The Cystic Fibrosis Foundation requests the committee allocate \$3 million in Federal funding in fiscal year 2008 to support much-needed expansion of our clinical research program, the Therapeutics Development Network (TDN), through the Coordinating Center at Children's Hospital & Regional Medical Center in Seattle, Washington. This will provide a significant investment in the Cystic Fibrosis Foundation's ongoing efforts to meet the demand for testing of all the promising new therapies for cystic fibrosis.

Designating Federal funding for the Cystic Fibrosis Therapeutics Development Network will accelerate testing of new therapies for CF. The TDN plays a pivotal role in accelerating the development of new treatments to improve the length and quality of life for cystic fibrosis patients. Since the Cystic Fibrosis Foundation established this program in 1998, the TDN has evaluated 12 new products, with seven more products now in clinical trials. Opportunities exist to pursue 10 additional trials on drug candidates in the next 18 months.

The CF Foundation has adopted an innovative business approach to drug discovery and development that is emulated by other nonprofits. Lessons learned from centralization of data management and analysis and data safety monitoring in the TDN will be useful in designing clinical trial networks in other diseases. Federal

funding to support the TDN will provide special insights regarding the most efficient means of conducting clinical trials on orphan diseases.

*National Center for Research Resources*

The Institutional Clinical and Translational Science Awards program is an initiative of particular importance to cystic fibrosis. This NIH Roadmap program administered by the National Center for Research Resources (NCRR) encourages novel approaches to clinical and translational research, enhances the utilization of informatics and strengthens the training of young investigators. The Cystic Fibrosis Foundation has enjoyed a productive relationship with the NCRR to support our vision for improving clinical trials capacity through its early financial support of the TDN.

SUPPORTING ADDITIONAL RESEARCH AREAS

While much of this testimony has focused on clinical research, these new therapies rely on solid basic research. Although the discovery of the CF gene in 1989 was an important step forward, there is still much to be learned about the disease. As a result, the CF Foundation continues to invest in basic research on the disease to deepen our knowledge of CF and to better understand how we may intervene in the disease course. There are several research projects at NIH that are essential to this work, and for which we express our strong support.

*Protein Misfolding and Mistrafficking*

The Cystic Fibrosis Foundation urges the NIH to devote special focus to research in protein misfolding and mistrafficking, an area which may yield significant benefits for CF and other diseases where misfolding is an issue. We applaud both the National Heart, Lung and Blood Institute (NHLBI), and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for their initiatives that target research on protein misfolding, and urge an aggressive commitment to facilitate continue exploration in this area to build upon promising discoveries. Additionally, we urge funding by the National Institute of General Medical Sciences (NIGMS) for the creation of tools and reagents and advances in techniques for precision monitoring of folding and trafficking events and for the sharing of resulting data that would complement the efforts of NIDDK- and NHLBI-funded investigations in this area.

On behalf of the Cystic Fibrosis Foundation, I thank the committee for its consideration. Congress has reason to be proud of its role in supporting NIH, which is the world's leader in biomedical research. The NIH has strong leadership to move into the new century, when we will see the translation of basic research into new treatments for many diseases. We believe the experience of the CF Foundation in clinical research can serve as a model for research on other orphan diseases, and we stand ready to work with NIH and congressional leaders.

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society would like to submit the following testimony regarding fiscal year 2008 Federal appropriations for biomedical research, with emphasis on appropriations for the National Institutes of Health. The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing over 14,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society is comprised of thousands of researchers who depend on Federal support for their careers and their scientific advances.

In April 2004 the Endocrine Society testified before the House Appropriations Committee. During this testimony the Society provided the committee with a grim picture of what might happen to NIH-funded research if the financial commitment made during the doubling period (1998–2003) was not sustained. Our testimony indicated that breakthroughs in areas of endocrine research—such as diabetes and obesity—were on the horizon after the doubling period, but that the breakthroughs were in jeopardy of being abandoned due to sharp decreases in NIH funding from Congress. Unfortunately, it seems our prognostication was correct.

Included as an addendum (Addendum A) to this testimony is an excerpt from a compelling article that appeared in the April issue of *Men's Health* magazine. Highlighted within this article is the story of Endocrine Society member, Alan Schneyer, Ph.D. This article examines the real life impact that reduced funding for NIH has on the Nation's researchers and their potential breakthroughs. Dr. Schneyer has been working in the field of endocrine research and has made promising discoveries

that could lead to future diabetes treatments. But as of April 2007 his lab, his research, and his employees have been shut down because his grant will no longer be funded. The great promise hoped for in 1997, at the beginning of the doubling period, has led to closed labs and unemployed scientists in 2007.

A simple glance at NIH funding trends over the last few years will show how this great promise led to great disappointment. Under the President's proposed fiscal year 2008 budget most NIH institutes and centers would see their budgets remain flat for the fourth year in a row. The proposed fiscal year 2008 NIH budget of \$28.7 billion would be down \$230 million from the recently finalized fiscal year 2007 budget. Worse yet, the NIH budget would fall 12 percent from 2004 to 2008 when adjusted for biomedical research inflation.

This funding downturn not only has a drastic impact on existing researchers such as Dr. Schneyer, but it is having a profound effect on future researchers as well. NIH projects the success rate for new renewal grant applications will stabilize at 20 percent in 2007 and 2008, down steeply from a high of 32 percent in fiscal year 2001. According to the American Association for the Advancement of Science, NIH expects to fund 1 in 5 applicants who apply for research funding in 2008. During the height of the doubling period NIH funded 1 in 3 applicants. As you can imagine, these trends send a chilling message to young researchers who were drawn to biomedical research during the doubling period. After years of steady support for biomedical research over the last decade, many young people were drawn into research labs, but now Federal funds are declining. As the funding declines, so too does the opportunity for young researchers. NIH is trying to address this issue with its Pathways to Independence program. This program would provide up to 5 years of support for scientists just beginning their research careers. We would encourage the committee to fully fund the Pathways to Independence program in fiscal year 2008.

The Endocrine Society recommends that the National Institutes of Health receive \$30.8 billion in fiscal year 2008. This increase of 6.7 percent will set NIH, and the researchers who depend on it for funding, on a 3-year track to recoup the losses caused by biomedical research inflation over the last 4 years.

While researchers will never guarantee cures from ongoing research, we do know that without adequate sustained Federal support the chances for breakthroughs are diminished. In fact very significant advances have been made; for example for the first time in our history death rates from cancer have started to decrease, which can be attributed to NIH funded research in previous decades. We ask that Congress stop the boom and bust funding cycles that have plagued NIH over the last 10 years and commit to a steady funding stream to keep the research of today on track to become the breakthroughs of tomorrow.

#### ADDENDUM A—MEN'S HEALTH—TONS OF USEFUL STUFF

##### THE BATTLE FOR YOUR HEALTH

As American soldiers fight terrorists overseas, another war is being lost at home: The one to cure disease and, ultimately, save your life.

*Boston, MA.*—The last thing Alan Schneyer, Ph.D., expected to find when he began manipulating the reproductive genes in mice was a possible cure for diabetes.

"We made these mice and thought they would be infertile, but they weren't," Schneyer tells me as we pace his sparse laboratory at Massachusetts General Hospital. "So we started looking at their other organs. Turns out, they have improved glucose tolerance and very little visceral fat. Boom! I thought, This is great. We can address a real disease."

Schneyer eyes the empty beakers, vials, and tubes, the dust beginning to gather on microscopes, tissue-holding minifridges, computer terminals. The mood is so grim I expect Edgar Allan Poe's valet to walk through the door. "Then we lost our grant. Normally you'd see six people working here. Now my fellows are gone. My technician is leaving at the end of the month. My associate works for someone else now." He looks at me and musters a half-hearted smile. "I'm out in April," he says.

Schneyer's is a familiar tale. Since a doubling of the National Institutes of Health (NIH) budget between 1997 and 2003—an increase, incidentally, that contributed to the discovery and mapping of the human genome—the agency's budget has flatlined at about \$28 billion for the past 3 years, outpaced by 9 percent inflation. When funds were cut by \$33 million in 2006, it marked the first time in more than 35 years that NIH appropriations actually decreased.

Schneyer, 52, is quick to note that his discovery might well have "come to a dead end." Still, with 73 million Americans either having diabetes or a high risk of it—and with the number of overweight children in America at 9 million and growing—it's frustrating to let any possible cure go unexplored. "We'll never know where my

research might have led, will we?” Schneyer says, adding that since the NIH started issuing research grants after World War II, “a good 75 percent” of discovered cures have come from government-funded programs like his—and not from drug-company labs. In fact, thanks to NIH-sanctioned research, we know that exercise promotes weight loss, high LDL cholesterol raises the risk of heart disease, chemotherapy kills cancer, and fluoride prevents tooth decay.

Now, Schneyer is left hoping for a last-minute reprieve. This is unlikely. The 2007 budget for the Department of Health and Human Services, under which both the CDC and NIH operate, shows that grant monies for “Preventive Health and Health Services,” “Public Health Improvement,” and “Children’s Hospitals” have been slashed by almost \$375 million. “Bioterrorism” funding, on the other hand, has increased to \$1.7 billion, up nearly tenfold in the past 5 years.

Like many medical researchers and physicians, Schneyer is angry with the Federal Government for shifting funds away from medical research and—“ostensibly,” he says—into the war on terror at home and abroad. It has not gone unnoticed in America’s medical community that as Federal grants stagnate or plunge, Washington politicians have, as of January, authorized more than \$315 billion—that’s \$6.5 billion a month, \$9 million an hour—to be spent in Iraq alone.

Then there are the seemingly insane items, recently reported by *Newsday*, in the Department of Homeland Security’s budget: \$18,000 to equip the Santa Clara, California, bomb squad with Segways; \$30,000 to ensure a defibrillator is on hand for every Lake County, Tennessee, high-school basketball game; \$500,000 worth of security gear to the town of North Pole, Alaska, population 1,778; Kevlar vests for the police dogs of Columbus, Ohio; the list goes on.

Sitting in Schneyer’s office, I motion toward the window. What would happen, I ask, if I walked into the tavern across the street and queried the first five patrons about whether Federal dollars would be better spent on body armor for soldiers, or research on the reproductive organs of mice?

“You’re not framing the question correctly,” he says. “Statistics indicate that two of the five men in the bar have already developed some form of cardiovascular disease. So you ask them how they feel about genetic research that might find a cure, so that their children don’t die of heart disease.

“It’s easy to ask why we’re funding work on a mouse organ, or on a worm. Well, you take that same gene and look for a similar one in a human, and suddenly, ‘Hey, it’s responsible for diabetes!’ It’s not a question of a cure for diabetes versus body armor for soldiers. This isn’t about medical science versus armor or, for that matter, school lunches, fire departments, or red lights at dangerous intersections. A smart government can fund it all.”

“Where will that money come from?” I ask.

Schneyer’s cheeks burn as he speaks of cost overruns in Iraq and the recent tax cuts. “Every medical-research experiment that is not done is an opportunity lost,” he says. “You don’t know which one is going to bring the eureka moment.”

He smiles, rueful. “Our country—the president, Congress—has to decide if it’s worth doing research that will lead to better health in the long run and lower costs for the next generation of Americans.

“The catchall excuse for the funding cuts is the war on terror. But al-Qaeda could attack New York, and that wouldn’t reduce the number of children with diabetes in Chicago and Miami and Detroit. Researchers who are on the verge of finding cures for Alzheimer’s, Parkinson’s, all kinds of cancers . . . their funding is all being cut.

“That’s a strange way to protect America.”

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#### PREPARED STATEMENT OF THE FAIR ALLOCATIONS IN RESEARCH FOUNDATION

The death rate in our country from AIDS has plummeted as evidenced in 2006 by the 99 percent drop in California’s newly infected AIDS patients<sup>1</sup> from just under 10,000 to 130 (as of 2/28/07) and the 93 percent drop to 100 in all of Illinois’s HIV/AIDS patients for 2004.<sup>2</sup> In addition, we respectfully bring to Chairman Byrd’s attention that this great success includes West Virginia where AIDS deaths have dropped to 23 for their latest reporting period (2005).<sup>3</sup> This success against AIDS

<sup>1</sup> <http://www.dhs.ca.gov/aids/Statistics/pdf/Stats2007/Feb07AIDSMerged.pdf> Page 2, CA Office of AIDS—patients infected in 2006 who died in 2006.

<sup>2</sup> [http://fairfoundation.org/states/illinois\\_AIDS\\_deaths.htm](http://fairfoundation.org/states/illinois_AIDS_deaths.htm)

<sup>3</sup> WVA Dept of Health, Tom Light, 304-558-1748 or [http://fairfoundation.org/states/west\\_virginia.htm](http://fairfoundation.org/states/west_virginia.htm)

is being repeated throughout America, yet AIDS still receives 10 percent of the entire National Institutes of Health (NIH) disease research budget.

Such exorbitant funding for AIDS has resulted in unfair allocations for all non-AIDS diseases, including the sixteen<sup>4</sup> that kill a million more Americans than AIDS annually. For example, cardiovascular disease kills almost a million Americans compared to 16,316 (2005)<sup>5</sup> for AIDS, yet the NIH is spending only \$40 on each CVD patient versus \$3,052 on each AIDS patient in research.<sup>6</sup> Diabetes kills more citizens than AIDS and breast cancer combined, yet only \$50 is spent on each diabetic in research. More AIDS patients are now dying of hepatitis C than they are of AIDS,<sup>7</sup> and hepatitis C (HCV) affects 4–5 times as many as AIDS yet only \$25 is allocated for each HCV patient.

Disease	2005 NIH research [Dollars in billions]	Deaths per disease	Dollars per patient death	Dollars per patient
HIV/AIDS .....	\$2.930	16,316	\$178,046	\$3,052
Cardiovascular Dis. ....	2.300	930,000	2,523	40
Diabetes .....	1.000	73,965	14,236	50
Alzheimer's Dis. ....	.642	63,343	10,182	143
Prostate Cancer .....	.373	27,350	13,638	192
Parkinson's Dis. ....	.205	17,898	12,403	148
Hepatitis C .....	.121	12,000	10,166	25
Hepatitis B .....	.036	5,000	6,600	32
COPD .....	.066	126,128	500	5
West Nile Virus .....	.063	161	390,304	14,932

Regardless if the funding comparison is measured utilizing “allocation per patient,” “allocation per death” or “total allocation” per disease, the great success of AIDS researchers has resulted in funding for AIDS now being disproportionate and inequitable.

In addition, hundreds of millions of dollars are raised for AIDS by celebrities and non-profit organizations (amfAR, etc.) while similar efforts do not exist for many other diseases. With the recent \$37 billion stock pledge by Warren Buffett to the \$29 billion Bill and Melinda Gates Foundation and Mr. Buffett's support for the Gates's bias in funding to combat HIV disease, the favoritism afforded this disease has reached excessive proportions. Indeed, Melinda Gates has stated that her fondest goal is a vaccine for HIV disease and to date the total funding by the Gates's Foundation for all HIV programs is \$6.5 billion. It is anticipated that much more of the Gates Foundation will go towards combating HIV disease in the future.

When one reflects that the total NIH bio-medical research budget for every disease known to man is only \$28.4 billion and 10 percent of that also goes to HIV research, one can only be dismayed at the continual favoritism afforded this illness.

The NIH has responded to The FAIR Foundation's requests to cease the favoritism afforded HIV/AIDS and to reallocate some of the present AIDS dollars to other diseases by referencing global AIDS and the fact that AIDS is communicable and destructive to the young.<sup>8</sup>

What are the solutions for global AIDS—more research? No, the answers to global AIDS are the same that have dropped the death rate throughout America, and they have been expressed by Presidents Clinton, Bush and the Director of the NIAID, Dr. Fauci, namely: preventive education, the drugs which converted AIDS from an acute illness into a chronic illness (HAART or Highly Active Anti-retroviral Therapy) and setting up health infrastructures.

Indeed, Dr. Fauci himself recently admitted the great success in HIV research when he stated on CNN, “. . . the scientific advancements that have been made in HIV [research] are breathtaking [with] highly effective drugs to suppress HIV to the point where what was a death sentence in the early eighties to now having patients who look and feel well, who are leading very productive, very gratifying lives . . .”

Regarding the “communicable” nature of AIDS, Congress must force realization upon the NIH that simply because an illness is “infectious” does not warrant disproportionate research funding. Patients suffering from non-communicable illnesses such as prostate disease, Alzheimer's disease, etc. should not be discriminated

<sup>4</sup> <http://www.fairfoundation.org/thesixteen.htm>

<sup>5</sup> [http://fairfoundation.org/CDC\\_AIDS\\_death\\_estimates\\_2001-2005.pdf](http://fairfoundation.org/CDC_AIDS_death_estimates_2001-2005.pdf)

<sup>6</sup> <http://www.fairfoundation.org/factslinks.htm>

<sup>7</sup> [http://fairfoundation.org/specter\\_letter\\_hcv\\_in\\_aids\\_pts.pdf](http://fairfoundation.org/specter_letter_hcv_in_aids_pts.pdf)

<sup>8</sup> <http://www.fairfoundation.org/nihletter.htm>

against because they cannot transmit their disease to others or because its etiology is congenital or acquired by environmental causes.

In America's youth, the CDC's 2005 report States seven deaths in patients age <13, 63 under age of 19 and 677 deaths under age 30. The estimated deaths from SIDS each year is 3,000. Clearly, HIV disease is not a major factor killing our youth.

An unrecognized factor negatively impacting all non-AIDS diseases is the "compounding effect" of present NIH policy. The present funding total of each disease may be viewed as their "principal balance" for this analogy. If the present effort by 100 Members of the House to increase NIH funding by 6.7 percent is successful, the increase in AIDS funding will be approximately \$194 million whereas Alzheimer's disease will receive only \$43 million and Chronic Obstructive Pulmonary Disease (COPD) \$4.4 million even though those two diseases kill, respectively, three and nine times more Americans than AIDS. Each year the additional increases in the "principle balance," or total funding, results in the "compounding interest effect" that increases the disproportionate funding for AIDS. Consequently, the gap in funding between AIDS and all other diseases grows even larger. Supplying greater funding to the NIH without redistribution of present inequities is unfair for non-AIDS illnesses.

The issue of AIDS favoritism is rapidly becoming a political issue. Before billions more dollars are spent on yet another preventive measure (HIV vaccine), we urge you to publicly call for a partial redistribution of the HIV excess funding to other illnesses that do not presently have effective treatments, including the 16 maladies [iii] that are killing a million more Americans than HIV disease annually.

Indeed, with the budgetary limitations resulting from our government's commitments, including supporting the war in Iraq and restoring the areas ravaged by hurricanes Katrina and Rita, necessary increases for bio-medical research funding have been non-existent. As with the common citizen whose budget is pinched, it is appropriate to reallocate existing funds, in this case some of HIV/AIDS funding to other illnesses.

Sixty-one million voters with cardiovascular disease, 21 million diabetics and millions of other constituents with non-AIDS illnesses will applaud your courageous declaration, while approximately 1 million with HIV/AIDS may be dismayed at such an announcement.

The FAIR Foundation (FAIR is an acronym for "Fair Allocations In Research) is a national organization representing thousands of members and supporters—concerned citizens—who want the success of AIDS advocates and AIDS researchers recognized with a corresponding change in the allocation priorities of the NIH with our taxpayer dollars that fund bio-medical research. Gay members of our country are present on our Board, including Ray Hill, who used to be one of this country's most strident HIV activists. Because of their great success, Ray, who has been named Houston's gay hero by that community 7 years in a row, now advocates for hepatitis C.

On behalf of our national membership we are respectfully requesting that a portion of AIDS research allocations be reevaluated and redistributed now that the existing medications and extensive prevention programs for this illness have significantly mitigated its threat.

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#### PREPARED STATEMENT OF THE FAMILIES USA GLOBAL HEALTH INITIATIVE'S

Families USA Global Health Initiative appreciates the opportunity to submit this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education concerning Federal funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). Our statement today speaks to the important role that NIH and CDC play in protecting and improving health in the United States and the world.

For more than 20 years, Families USA has advocated for changes in U.S. policies to increase access to affordable health care, especially for low-income individuals. The Global Health Initiative was launched in 2006 to advocate for increased U.S. investment in research and development of medical interventions targeting infectious diseases that disproportionately affect populations in low-income countries ("global health" research).

The government must step in to support global health research and development because there is little private industry interest in filling the current void, an overwhelming human need, a long history of underfunding, and it's in our Nation's self-interest to do so.

## OVERWHELMING HUMAN NEED AND HISTORIC UNDERFUNDING

Research addressing global health crises has been historically underfunded. More than 500 million people contract malaria each year. NIH spends just 0.3 percent of its budget on malaria research. CDC's malaria extramural research program was cut.

Nine million people develop active tuberculosis (TB) each year, 2 million die from TB, and extensively drug-resistant strains poses a substantial domestic and world-wide health threat. NIH spends just 0.5 percent of its budget on tuberculosis. The Global Health section of CDC's Proposed fiscal year 2008 Budget, submitted to the Congress, contains no mention of work on TB.

More than 1 billion people living in tropical and subtropical climates around the world are stricken with devastating, debilitating parasitic diseases that receive so little research funding that the World Health Organization and others in the medical community refers to these conditions as "neglected" tropical diseases.

Almost 40 million people around the world are currently infected with HIV. Only 2.5 percent of NIH's budget is devoted to research on preventative medical interventions, including vaccines and microbicides. CDC's global HIV/AIDS activities are limited primarily to support of the President's Emergency Plan for AIDS Relief (PEPFAR). Although PEPFAR is expanding access to existing HIV/AIDS treatments for many in need, PEPFAR alone will not curb the global AIDS pandemic. More than 4 million people become newly infected each year and existing treatments are becoming increasingly ineffective due to drug resistance. Vaccines and microbicides, along with improved treatments, are needed to curtail the global AIDS pandemic.

## OUR NATIONAL INTEREST

When NIH and CDC are insufficiently funded, as has consistently been the case in recent years, they are forced to fight global health crises with one hand tied behind their back. This has serious health, economic, and political implications—not just internationally, but also domestically. There are also compelling diplomatic and humanitarian reasons for funding NIH's and CDC's global health work.

First, we have a national health interest in ensuring that NIH and CDC have all the resources that they need. Diseases can easily spread across international borders; epidemics abroad, including lethal strains of extremely drug-resistant TB, can lead to cases here at home. Americans who travel abroad, including our troops, are also at risk of contracting infectious diseases that are endemic in other countries.

Second, we have a national economic interest in providing NIH and CDC with all the resources that they require. In regions where HIV/AIDS, malaria, and TB prevalence are greatest, countries' entire workforces suffer from substantially reduced productivity and economic growth is hindered. With globalization, countries' economic health is intertwined. The economic toll of diseases hurts world economic growth and limits trade, and it reduces markets for U.S. goods.

Third, we have a national political interest in giving NIH and CDC the funding needed to combat infectious diseases with a massive global burden. In areas of the world where the infectious disease burden is greatest, enormous numbers of people are getting sick and dying. Populations are being decimated. The social structures of entire countries has been unraveling, paving the way for political unrest and the undermining of democracy in entire regions of the world.

Fourth, we have a national diplomatic interest, and there are strong humanitarian reasons as well, for funding NIH's and CDC's work in preventing and controlling diseases that burden millions of people around the world. As the wealthiest country on earth, we have the means to advance health and alleviate human suffering. Using our wealth to improve global health improves America's image and serves as a very effective foreign policy tool.

## FUNDING RECOMMENDATIONS

*All NIH Institutes and Centers*

Families USA Global Health Initiative recommends 6.7 percent annual increases to NIH's total budget from fiscal year 2008 to fiscal year 2010 (including 3.7 percent adjustments each year for annual rises in biomedical inflation, plus an additional 3.0 percent each year to start to correct for the failure in recent years to keep up with inflation).

In recent years, NIH funding has fallen further and further behind the rising costs of biomedical research. This means that less research gets funded and medical progress is delayed. Only 16.7 percent of new grant applications were funded in 2006—an 83 percent failure rate. Many scientists are sitting on the sidelines, unable to develop promising ideas that could lead to an effective AIDS vaccine, im-

proved tuberculosis treatments, and other medical interventions that could improve the lives of millions worldwide.

A 6.7 percent annual increase for all NIH Institutes and Centers, for each year from fiscal year 2008 to fiscal year 2010, would adjust NIH funding for anticipated annual rises in inflation and add a modest 3.0 percent rise to help make up for losses in inflation-adjusted funding experienced by all of NIH in recent years.

#### *Additional Increase for NIH Global Health Programs*

Families USA Global Health Initiative recommends that Congress begin to rectify, over a 7 year period, historic underfunding of global health programs by increasing the National Institute of Allergy and Infectious Diseases and Fogarty International Center budgets annually by 2.9 percent for each year from fiscal year 2008 to fiscal year 2014.

This increased annual 2.9 percent investment in global health would be apart from, and in addition to, the 6.7 percent increases over the next 3 years for all NIH Institutes and Centers, and annual inflationary adjustments provided thereafter.

The National Institute of Allergy and Infectious Diseases (NIAID) has taken a leadership role in the bulk of global health research and development activities undertaken at NIH. Robust funding for NIAID is essential for addressing infectious disease crises around the globe and in the United States.

The John E. Fogarty International Center (FIC) also plays a crucial role in addressing global health challenges by facilitating collaboration between United States and international researchers through its international training and global health research capacity building programs. FIC's programs facilitate the development of medical discoveries worldwide.

Malaria and tuberculosis research, combined, comprise less than 1 percent of the National Institutes of Health's total budget. Last year, cuts to the NIH budget resulted in funding being completely cut to 11 HIV/AIDS clinical trials in the United States. FIC's fiscal year 2006 funding constituted a miniscule 0.23 percent of NIH's total budget.

A 2.9 percent additional increase for NIAID and FIC, for each year from fiscal year 2008 to fiscal year 2014—apart from and on top of the 6.7 percent annual increases for all of NIH from fiscal year 2008 to fiscal year 2010, and inflationary increases thereafter—is badly needed to make up for historic underfunding for global health research and to achieve progress in the development of new interventions for diseases devastating millions worldwide.

#### *Centers for Disease Control and Prevention*

Families USA Global Health Initiative supports the CDC Coalition's recommendation of increasing CDC's total budget to \$10.7 billion in fiscal year 2008 and further recommends that Congress appropriate \$512 million in fiscal year 2008 for CDC's global health work (4.8 percent of CDC's \$10.7 billion total budget).

CDC's global health programs are vitally important to protecting Americans and people around the world from disease. Cuts to CDC's budget undermine both the United States and the global public health infrastructures that are crucial to rapidly responding to new disease outbreaks and combating existing global pandemics.

Yet, some of CDC's global health programs have been flat-funded for years; other global health programs can no longer carry out their critical mission due to limited funds. For instance, CDC currently has no appropriated budget for global tuberculosis activities and the malaria extramural research program had to be phased out due to insufficient funds. Moreover, failure to adequately fund CDC's global health work has broader implications for the success of other United States funded initiatives, including PEPFAR and the President's Malaria Initiative (PMI).

At a global health funding level of \$512 million in fiscal year 2008, CDC would be able to support crucial global disease surveillance and control programs; perform research to improve existing medical interventions; and develop new interventions for diseases where interventions are currently lacking.

#### CALL FOR ACTION

Americans across the country, and people from around the world, are looking to NIH and CDC for new medical advances that will lead to a healthier tomorrow. Shortchanging NIH and CDC places America's—and the world's—health at risk. We urge the subcommittee to fund NIH and CDC at the levels specified above.

For additional information, please contact Janet Goldberg at 202-628-3030 or [jgoldberg@familiesusa.org](mailto:jgoldberg@familiesusa.org).

## PREPARED STATEMENT OF FIGHT CRIME: INVEST IN KIDS

Mr. Chairman and members of the subcommittee: Thank you for the opportunity to submit this written testimony. My name is Dennis Conard and I am the Sheriff in Scott County, IA (Davenport), where I have served in law enforcement for almost 35 years. I am also a graduate of the FBI National Academy, the National Sheriffs' Institute and the Iowa Law Enforcement Academy and a member of the National Sheriffs' Association. I am also one of the 3,000 police chiefs, sheriffs, prosecutors, and victims of violence of FIGHT CRIME: INVEST IN KIDS—a non-profit anti-crime organization that has come together to take a hard-nosed look at the research about what really works to keep kids from becoming criminals.

The law enforcement leaders of FIGHT CRIME: INVEST IN KIDS know that dangerous criminals must be prosecuted and put behind bars. But we also know better than anyone that we cannot arrest and imprison our way out of the crime problem. No prison can bring back a murdered wife, mother or child, and no punishment can undo a crime victim's anguish. Fortunately, research—and our experiences on the front lines in the fight against crime—show that targeted investments can help kids get a good start in life. We could be saving thousands of lives and preventing thousands of crimes by increasing our investments in cost-effective, proven crime-prevention programs.

Four types of proven crime-prevention approaches are outlined in FIGHT CRIME: INVEST IN KIDS' "School and Youth Violence Prevention Plan":

- quality early childhood education;
- child abuse and neglect prevention programs;
- quality after-school; and
- prevention and intervention programs to get troubled kids back on track.

As you know, the first three areas fall within your Appropriations Subcommittee's jurisdiction. Since both the research and my years of experience on the front lines in the fight against crime show that these approaches help stop crime in its tracks, I urge you to increase our Nation's investments in these proven strategies for saving lives and taxpayer dollars.

## EARLY CHILDHOOD EDUCATION AND CARE

By now, most people know that Head Start and quality child care help close the achievement gap. But few people are aware of the amazing impact of early education programs on later criminality. A Journal of the American Medical Association-published study of Chicago's government-funded Child Parent Centers, which have served more than 100,000 3- and 4-year-olds, showed that children who did not participate in the program were 67 percent more likely to have been retained a grade in school and 71 percent more likely to have been placed in special education. But equally impressive, the study showed that kids who did not participate were 70 percent more likely to be arrested for a violent crime by age 18. Similarly, at-risk kids who were left out of the high-quality High/Scope Perry preschool program were five times more likely to be chronic offenders (more than four arrests) by age 27 than those who participated.

By improving outcomes for kids, quality early childhood education also saves money. The High/Scope Perry Preschool program saved \$17 for every \$1 spent. An analysis by Arthur Rolnick of the Federal Reserve Bank of Minneapolis shows that the program's annual return on investment is 16 percent after adjusting for inflation. Seventy-five percent of that return goes to taxpayers in the form of decreased special education expenditures, crime costs and welfare payments. In comparison, the long-term average return on U.S. stocks is 7 percent after adjusting for inflation. Thus, an initial investment of \$1,000 in a program like Perry Preschool is likely to return more than \$19,000 in 20 years, while the same initial investment in the stock market is likely to return less than \$4,000.

However, due to lack of State and Federal financial resources, there remains significant unmet need with only about half of eligible poor kids nationally served by Head Start and less than 5 percent of eligible infants and toddlers in Early Head Start. Only one in seven kids in eligible, low-income families receives help from the Child Care and Development Block Grant to pay for the quality child care that can help ensure they are on the path toward being a productive, taxpaying adult rather than a burden on taxpayers and part of our criminal justice system. Funding has been stagnant over the last several years. By the administration's own estimates, 150,000 fewer children receive child care assistance now than in 2000.

I urge Congress to:

- Increase funding for Head Start by at least \$750 million to restore funding for services to kids to the fiscal year 2002 level.

—Increase discretionary funding for the Child Care and Development Block Grant by \$720 million to restore funding for services to kids to the fiscal year 2002 level.

This is the first step toward meeting the unmet need and further strengthening the quality of early childhood care and education.

#### CHILD ABUSE AND NEGLECT PREVENTION PROGRAMS

The best available research indicates that, based on confirmed cases of abuse and neglect in just 1 year, an additional 35,000 violent criminals and more than 250 murderers will emerge as adults who would never have become violent criminals if not for the abuse or neglect they endured as kids.

Fortunately, quality, voluntary in-home parent coaching can help stop this cycle of violence. Voluntary, in-home parent coaching (or “home visiting”) programs help new parents get the information, skills and support they need to be better parents and promote healthy child development. One program, the Nurse Family Partnership (NFP), has been shown to cut child abuse and neglect of at-risk children in half and reduce kids’ and moms’ later arrests by about 60 percent—saving an average of \$28,000 (net) for each family in the program.

As a first step toward meeting this need, I urge Congress to provide:

- \$100 million to expand and improve in-home coaching programs like those that would be supported under the Education Begins at Home Act (S. 667), which is expected to be enacted this year.
- \$545 million (the combined mandatory and discretionary authorized level) for the Promoting Safe and Stable Families program to help communities run in-home parent coaching programs, parenting-education programs, family-strengthening services for troubled families, adoption services, and other child abuse and neglect prevention programs.
- \$200 million (the authorized level) for the Child Abuse Prevention and Treatment Act to help improve State child protection services and community-based prevention services.
- \$1.7 billion (rejecting the administration’s proposed cuts) for the Social Services Block Grant (SSBG), the Federal Government’s single largest support for child welfare services.

#### AFTER-SCHOOL PROGRAMS

In the hour after the school bell rings, violent juvenile crime soars and the prime time for juvenile crime begins. The peak hours for such crime are from 3:00 p.m. to 6:00 p.m. These are also the hours when children are most likely to become victims of crime, be in an automobile accident, smoke, drink alcohol, or use drugs. After-school programs that connect children to caring adults and provide constructive activities during these critical hours are among our most powerful tools for preventing crime. For example, a study compared five housing projects without Boys & Girls Clubs to five receiving new clubs. At the beginning, drug activity and vandalism were the same. But by the time the study ended, the projects without the programs had 50 percent more vandalism and scored 37 percent worse on drug activity. Despite these proven benefits, more than 14 million children nationwide still lack adult supervision after school.

The 21st Century Community Learning Centers program (21st CCLC) awards grants to communities to establish after-school programs that provide constructive activities for kids. Since being funded at \$1 billion in fiscal year 2002, there have been no real funding increases for 21st CCLC. In fiscal year 2007, the program received \$981 million—far below the program’s \$2.5 billion authorization under the No Child Left Behind Act. I urge Congress to:

- Substantially increase funding for the 21st Century Community Learning Centers to support and expand after-school programs that offer kids constructive activities during the peak hours of violent juvenile crime, 3:00 pm to 6:00 pm. Also, I urge you to authorize at least an additional \$500 million for programs for at-risk middle and high school students who now experience the greatest unmet need—and are at greatest risk of perpetrating or being victims of crime.

#### LAW ENFORCEMENT LEADERS ARE UNITED

The members of FIGHT CRIME: INVEST IN KIDS, along with major national law enforcement associations, have adopted forceful calls for public officials to ensure access to quality early care and education, provide adequate funding to prevent child abuse and neglect, and ensure access to after-school programs. If we do not invest in research-proven crime-prevention programs for America’s most vulnerable kids, many of them will grow up to become America’s most wanted adults. By failing

to adequately invest in proven crime-prevention strategies, Congress is not only failing to promote the well-being of millions of kids but is also permitting the cultivation of criminals—jeopardizing the safety of all Americans for years to come.

Thank you for this opportunity to present our views on how your subcommittee can help to reduce crime and make us all safer.

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#### PREPARED STATEMENT OF THE FOSTER GRANDPARENT PROGRAM

Mr. Chairman and members of the subcommittee, thank you for the opportunity to submit this testimony in support of fiscal year 2008 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNS). NAFGPD is a membership-supported professional organization whose roster includes the majority of more than 350 directors, who administer Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP.

Mr. Chairman, I would like to begin by thanking you and the distinguished members of the subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this subcommittee has always been there to protect the integrity and mission of our programs. Our volunteers and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. I also want to acknowledge your outstanding staff for their tireless work and very difficult job they have to “make the numbers fit”—an increasingly difficult task in this budget environment.

#### ADMINISTRATION’S REQUEST FOR FGP

Although the number of older people in America eligible to serve as Foster Grandparent volunteers is increasing by leaps and bounds as the “Baby Boomer” cohort ages, we were extremely disappointed to learn that—instead of seeking an increase for FGP to enable FGP to engage more low-income seniors in service—the administration has proposed slashing funding for FGP by \$13.387 million—a 12.1 percent cut.

#### IMPACT OF THE ADMINISTRATION’S PROPOSED FUNDING CUT

FGP is the only program in existence today that actively seeks out, trains, enables, places and supports the elderly poor in contributing to their communities by changing the lives of children who desperately need one-on-one attention. If enacted, this request will have a devastating effect on FGP programs nationwide:

- 3,150 low-income Foster Grandparent volunteers—over 10 percent of the current volunteer complement—will be cut permanently, slashing the total number of Foster Grandparent volunteers from 30,550 to 27,400. This will happen at a time when the number of FGP volunteers has not increased appreciably in 10 years!
- Local communities will lose over 3.3 million hours of volunteer service annually.
- Approximately 35,000 fewer children with special needs will receive the critical services provided by Foster Grandparents.
- FGP will permanently lose 3,000 Volunteer Service Years (VSJs, or volunteer “slots”). For each volunteer “slot” that is cut from a Foster Grandparent Program, that program will lose approximately \$4,500 from its Federal grant. In addition, at least \$500 in valuable non-federal resources contributed by communities will also be lost for every volunteer position that is eliminated.
- Low-income Baby Boomers will be excluded from serving as Foster Grandparents, because there will be no funds available to hire and place new volunteers as they reach the age of 60. According to the administration on Aging, there are currently 6,000,000 low-income seniors eligible for FGP; in 20 years, there will be 13,000,000!

This cut will take FGP back 7 years, to a funding level that is more than \$1 million less than its funding level in fiscal year 2001. In addition, the cut will take effect at a time when the average Federal grant for FGP has increased a miniscule \$2,898—or .875 percent (seven-eighths of 1 percent!)—since fiscal year 2003. After 4 years of flat funding, this 12.1 percent cut will not only cut volunteer numbers, it will also dig deeply into funds needed to sustain quality staff and quality programs. As a result, some FGPs may actually close, and local sponsoring agencies—

short of funds themselves and unable to contribute the funds needed to make up the cut—may simply relinquish their sponsorship.

The Corporation for National and Community Service's Budget Justification states that this cut can be absorbed merely through volunteer attrition. The reality is that the majority of FGPs nationwide will be forced to cut precious volunteers from their volunteer rosters. Whether a volunteer leaves through attrition or because there is no funding for his/her position, the fact is that this budget proposal will result in 3,150 fewer low income elders serving as Foster Grandparents.

NAFGPD respectfully requests three things of the subcommittee:

(1) to provide \$115.937 million for the Foster Grandparent Program in fiscal year 2008, an increase of \$5.000 million over the fiscal year 2006 and fiscal year 2007 levels of funding for the program and an \$18.387 million increase over the administration's fiscal year 2008 Budget Request for FGP. This critical funding will ensure the continued viability of the Foster Grandparent Program, and allow for important expansion of this unique program. Specifically, this proposal would fund a 3 percent cost of living increase for every Foster Grandparent Program as well as expansion grants to existing programs that would add 370 new low-income senior volunteers to serve 3000 additional children;

(2) to maintain current appropriations statutory language that prohibits CNCS from using funds in the bill to pay non-taxable stipend to volunteers whose incomes exceed 125 percent of the national poverty level. Congress has repeatedly over the last 7 years re-affirmed that the non-taxable stipend must be reserved for low-income volunteers. We ask that you again protect the mission of the Foster Grandparent and Senior Companion Programs—to enable low-income older people to serve their communities—by maintaining this important statutory language.

(3) to oppose administration proposals that would consolidate National and Community Service Act and DVSA accounts and set aside provisions of section 412 of the DVSA as they apply to the RSVP program (Title II, Part A), and, instead, direct that the changes proposed shall not be implemented prior to passage of a bill by the authorizing committees of jurisdiction specifying such changes.

#### FGP: AN OVERVIEW

Established in 1965, the Foster Grandparent Program was the first federally funded, organized program to engage older volunteers in significant service to others. It remains today the only volunteer program in existence that enables seniors living on very low incomes to serve as community volunteers by providing a small non-taxable stipend that allows volunteers to serve at little or no cost to themselves. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises nearly 350 programs in every State and the District of Columbia, Puerto Rico, and the Virgin Islands. These programs are now primarily in community-based child caring agencies or organizations—where most special needs children can be found today—and are administered locally through a non-profit organization or agency and Advisory Council comprised of community citizens dedicated to FGP and its mission. FGP represents the best in Federal partnerships with local communities, with Federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. Through this partnership and the flexibility of the program, FGP is able to meet the immediate needs of the local communities. This was demonstrated by Foster Grandparent Programs in communities that were impacted by the influx of Hurricane Katrina evacuees. Foster Grandparents rallied to provide services to children in shelters, child care centers, and schools.

#### FGP: THE VOLUNTEERS

There are currently 30,500 Foster Grandparent volunteers who give 31 million hours annually to more than 264,000 children, including 6,300 children of prisoners through 10,200 local agencies. FGP is a versatile, dynamic, and uniquely multi-purpose program. The program gives Americans 60 years of age or older who are living on incomes at or less than 125 percent of the poverty level the opportunity to serve 15 to 40 hours every week and use the talents, skills and wisdom they have accumulated over a lifetime to give back to the communities which nurtured them throughout their lives. FGP provides intensive pre-service orientation and at least 48 hours of ongoing training every year to keep volunteers current and informed on how to work with children who have special needs.

#### FGP: THE CHILDREN

Through our volunteers, FGP also provides person-to-person service to children and youth under the age of 21 who have special or exceptional needs, many of whom

face serious, often life-threatening challenges. The Foster Grandparent is very often the only person in a child's life who is there every day, who accepts the child, encourages him no matter how many mistakes the child makes, and focuses on the child's successes.

Special needs of children served by Foster Grandparents include AIDS or addiction to crack or other drugs; abuse or neglect; physical, mental, or learning disabilities; speech, or other sensory disabilities; incarceration and terminal illness. Of the children served, 7 percent are abused or neglected, 25 percent have learning disabilities, and 10 percent have developmental delays. FGP focuses its resources in areas where they will have the most impact: early intervention services and literacy activities. Nationally, 90 percent of the children served by Foster Grandparents are under the age of 12, with 39 percent of these children age 5 or under. Foster Grandparents work intensively with these very young children to address their problems at as early an age as possible, before they enter school. Nearly one-half of FGP volunteers serve nearly 12 million hours annually addressing literacy and emergent-literacy problems with special needs children.

Activities of the FGP volunteers with their assigned children include teaching parenting skills to teen parents; providing physical and emotional support to babies abandoned in hospitals; helping children with developmental, speech, or physical disabilities develop self-help skills; reinforcing reading and mathematics skills; and giving guidance and serving as mentors to incarcerated or other youth.

#### FGP: THE VOLUNTEER SITES

The Foster Grandparent Program provides child-caring agencies and organizations offering services to special-needs children with a consistent, reliable, invaluable extra pair of hands 15 to 40 hours every week to assist in providing these services. Seventy-one percent of FGP volunteers serve in public and private schools as well as sites that provide early childhood pre-literacy services to very young children, including Head Start.

#### FGP: COST-EFFECTIVE SERVICE

Using the Independent Sector's 2005 valuation for 1 hour of volunteer service (\$18.03/hour), the value of the service given by Foster Grandparents annually is over \$503 million, and represents a 4-fold return on the Federal dollars invested in FGP. The annual Federal cost for one Foster Grandparent is \$3,960—less than \$4.00 per hour. FGP's fiscal year 2006 Federal allocation was matched with \$37.4 million in non-federal donations from States and local communities in which Foster Grandparents volunteer. This represents a non-federal match of 34 percent, or \$.34 for every \$1.00 in Federal funds invested—well over the 10 percent local match required by law.

#### NAFGPD'S FISCAL YEAR 2008 BUDGET REQUEST

Given the dramatically expanding number of low-income seniors eligible to serve and the staggering number of troubled and challenged children in America today, we respectfully request that the subcommittee provide \$115.937 million for the Foster Grandparent Program in fiscal year 2008, an increase of \$5.000 million over fiscal year 2006 and fiscal year 2007 funding levels. This critical funding will ensure the continued viability of the Foster Grandparent program, and allow for an expansion of this important program. It will generate opportunities for approximately 370 new low-income senior volunteers to contribute 390,000 hours of service annually to nearly 3,000 additional children with special needs through Program of National Significance (PNS) grants to existing FGPs. The requested increase would be allocated for the following purposes, in order of priority: 1st: in accordance with the Domestic Volunteer Service Act (DVSA), designate one-third of the increase over the fiscal year 2006 and fiscal year 2007 level to fund Program of National Significance (PNS) expansion grants to allow existing FGP programs to expand the number of volunteers serving in areas of critical need as identified by Congress in the DVSA. 2nd: use all remaining funds to award an administrative cost increase of at least 3 percent to each existing Foster Grandparent Program in order to maintain quality, enable recruitment and sustain the work already being done by programs. The last time FGPs in the field realized any increases at all to cover the increased costs of doing business—especially in the area of transportation costs—was in fiscal year 2005; that increase amounted to a very small .84 percent, when inflationary price increases have been averaging 2–3 percent annually.

We request that no funds be provided for Senior Demonstration, and that language that expressly prohibits the payment of a non-taxable stipend to individuals whose incomes exceed 125 percent of the national poverty level continue to be in-

cluded in the appropriations statute as it has been since fiscal year 2000. This important language protects the purpose of FGP: to enable low-income elders to serve their communities at little or no cost to themselves.

The message is clear: (1) the population of low-income seniors available to volunteer 15 to 40 hours every week is increasing; (2) communities need and want more Foster Grandparent volunteers and more Foster Grandparent Programs. The subcommittee's continued investment in FGP now will pay off in savings realized later, as more seniors stay healthy and independent through volunteer service, as communities save tax dollars, and as children with special needs are helped to become contributing members of society.

Mr. Chairman, in closing I would like to again thank you for the subcommittee's support and leadership for FGP over the years. NAFGPD believes that you and your colleagues in Congress appreciate what our low-income senior volunteers accomplish every day in communities across the country.

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LETTER FROM THE FSH SOCIETY, INC.

JANUARY 24, 2007.

Senator TOM HARKIN,  
*Chairman, Subcommittee on Labor, HHS, Education and Related Agencies U.S. Senate, Washington, DC.*

DEAR HON. TOM HARKIN: I request the opportunity to testify in writing or in person before your Subcommittee on Labor, Health and Human Services, Education and Related Agencies regarding the fiscal year 2008 appropriations to the National Institutes of Health (NIH) for research on FSH muscular dystrophy.

The FSH Society requests the opportunity to update your committee on the progress made by the NIH over the past several years in FSH muscular dystrophy. Despite a growth in funding from \$7 million to \$75 million between 1991 and 2007 for research in muscular dystrophy across all Federal agencies, funding for our dystrophy is still anemic. The NIH now has perhaps a half dozen grants for FSH Dystrophy out of some 200 grants for muscular dystrophy in the NIH portfolio. FSHD is the third most common disease of muscle.

The NIH still needs encouragement and funding to develop a comprehensive research portfolio for FSHD. We are most appreciative of your support in this area and for the gains made thus far. It has always been an honor to participate in the hearing process.

The FSH Society, Inc. and the tens of thousands of patients it represents hope you will enable us by affording us the opportunity to present testimony to your subcommittee. It is most important to speak this year and to provide constructive input on this issue.

Sincerely,

DANIEL PAUL PEREZ,  
*President & CEO, FSH Society, Inc.*

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PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES  
ADMINISTRATION

The Friends of the Health Resources and Services Administration (HRSA) is an advocacy coalition of more than 100 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. Our member organizations strongly support the programs at HRSA designed to ensure access to health services for each person in the United States.

Through its programs in thousands of communities across the country, HRSA provides a health safety net for medically underserved individuals and families, including 45 million Americans who lack health insurance; 49 million Americans who live in neighborhoods where primary health care services are scarce; African American infants, whose infant mortality rate is more than double that of whites; and the estimated 850,000 to 950,000 people living with HIV/AIDS. Programs to support the underserved place HRSA on the front lines in responding to our Nation's racial/ethnic and rural/urban disparities in health status. HRSA funding goes where the need exists, in communities all over America. We support a growing trend in HRSA programs to increase flexibility of service delivery at the local level, necessary to tailor programs to the unique needs of America's many varied communities. The agency's overriding goal is to achieve 100 percent access to health care, with zero disparities. In the best professional judgment of the members of the Friends of HRSA, to re-

spond to this challenge, the agency will require an overall funding level of at least \$7.5 billion for fiscal year 2008.

The Friends of HRSA are gravely concerned about the president's budget recommendation of devastating cuts for fiscal year 2008, including over 12 program eliminations. This is in addition to the programs that were eliminated in the fiscal year 2006 and 2007 budget cycles and other programs that received deep cuts in both years.

Through its many programs and initiatives, HRSA helps countless individuals live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled change in the Nation's health care delivery system. HRSA could be well positioned to meet these new challenges as it continues to provide needed health care to the Nation's most vulnerable citizens.

The Primary Care Bureau received a \$207 million increase over the fiscal year 2007 current funding level, all of which is designated for the Community Health Centers adding 342 new or expanded health center service sites and bringing the number of patients served annually to 16.3 million. Community health centers, often in partnership with National Health Service Corps clinicians, form the backbone of the Nation's safety net. More than 4,000 of these sites across the Nation provide needed primary and preventive care to over 15 million poor and near-poor Americans. HRSA primary care centers include community health centers, migrant health centers, health care for the homeless programs, public housing primary care programs and school-based health centers. Health centers provide access to high-quality, family-oriented, culturally and linguistically competent primary care and preventive services, including mental and behavioral health, dental and support services. Nearly three-fourths of health center patients are uninsured or on Medicaid, approximately two-thirds are people of color, and more than 85 percent live below 200 percent of the poverty level. 2,700 clinicians in the National Health Service Corps deliver a significant portion of the primary care services provided at health centers. Corps members work in communities with a shortage of health professionals in exchange for scholarships and loan repayments. While recent growth in the health centers program has been substantial, a significant need remains in underserved communities across the country—we encourage the committee to continue its support of existing health centers and efforts to expand the reach and scope of health centers into new communities.

Health professions and nursing education programs, authorized under Titles VII and VIII of the Public Health Service Act, are essential components of America's health care safety net, filling the gaps in the health professions' supply not met by traditional market forces. Through loans, loan guarantees, scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and VIII health professions programs are the only Federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce. The programs provide support for the training of physicians, nurses, dentists, physician assistants, nurse practitioners, public health personnel, psychologists, and other allied health providers. The final budget for fiscal year 2006 included a 51.5 percent cut to Title VII; the \$40 million increase in the recently enacted fiscal year 2007 joint funding resolution does not fully recover the funding lost as a result of this devastating cut. Moreover, the President's fiscal year 2008 budget proposes an additional 94.6 percent cut to Title VII and a 29.7 percent cut to Title VIII. We are concerned that cuts to the health professions programs will exacerbate existing provider shortages in rural, medically underserved, and federally designated health professions shortage areas and impede recruitment of underrepresented minorities and students of disadvantaged backgrounds into the health professions. Adequate funding for HRSA Health Professions Programs under Title VII and VIII will help to create a prepared national workforce by working to reverse projected nationwide shortages of physicians, nurses, pharmacists, and other professionals. We strongly encourage the subcommittee to restore funding to these vital Health Professions programs.

The Maternal and Child Health Block Grant is a source of flexible funding for States and territories to address their unique needs, and remains in great need of increased funding. The Title V Maternal and Child Health Block (MCH) Grant received a \$31 million cut in the fiscal year 2006 budget and stagnant funding for fiscal year 2007. The President's budget for fiscal year 2008 proposed level funding for the block grant at the fiscal year 2006 level. Greater needs among pregnant women, infants, and children, particularly those with special health care needs present daunting challenges to the State maternal and child health programs. Furthermore, if programs like the Traumatic Brain Injury program, Universal Newborn Hearing Screening, and Emergency Medical Services for Children program are eliminated,

those costs will be borne by the MCH Block Grant. Of the nearly 4 million mothers who give birth annually, almost half receive some prenatal or postnatal service from a MCH-funded program. MCH programs increase immunizations and newborn screening, reduce infant mortality and developmentally handicapping conditions, prevent childhood accidents and injuries, and reduce adolescent pregnancy.

Research indicates that 50,000 individuals die as a result of Traumatic Brain Injury (TBI) each year in the United States and an additional 80,000 survive with residual long-term impairments. Today over 5.3 million Americans are living with a TBI-related disability. TBI can strike at anyone at any time—from falls, vehicle crashes, sports injuries, violence, and other causes. HRSA's Traumatic Brain Injury program makes grants to States to coordinate, expand and enhance service delivery systems in order to improve access to services and support for persons with TBI and their families. Despite increasing numbers of soldiers returning from war with head injuries, increasing numbers of children being identified as disabled due to head injuries, and the release of an Institute of Medicine Report stating the importance of the program to brain injury survivors and their families, the administration's fiscal year 2008 budget eliminates the TBI State Grant program. We encourage the subcommittee to restore funds that were cut from the TBI State Grant program. Individuals with traumatic brain injury have an array of protection and advocacy needs, including assistance with returning to work; finding a place to live; accessing needed supports and services, such as attendant care and assistive technology; and obtaining appropriate mental health, substance abuse, and rehabilitation services.

The Children's Health Act of 2000 authorized funding for grants and programs to improve state-based newborn screening. Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal and functional conditions in newborns. Screening detects disorders in newborns that, if left untreated, can cause death, disability, mental retardation and other serious illnesses. Parents are often unaware that while nearly all babies born in the United States undergo newborn screening for genetic birth defects, the number and quality of these tests vary from State to State. The March of Dimes, the American Academy of Pediatrics and the American College of Medical Genetics recommend that at a minimum, every baby born in the United States be screened for a core group of 29 treatable conditions regardless of the State in which the infant is born. Currently, Federal support for State newborn screening activities is provided through the Maternal and Child Health Block Grant, Special Projects of Regional and National Significance (SPRANS). We encourage the subcommittee to increase funding for newborn screening to assist States in improving their newborn screening programs and override the administration's proposed elimination of the universal newborn hearing screening program.

The proposed elimination of the Emergency Medical Services for Children (EMSC) program, a national initiative designed to reduce child and youth disability and death due to severe illness and injury, is also of great concern, especially in light of the recent Institute of Medicine report that highlighted significant shortcomings in pediatric emergency care. EMSC grants fund improvements to existing emergency medical services systems and to develop and evaluate improved procedures and protocols for treating children. Children are not merely small adults; they have unique and specific concerns that this programs works to address. We request that the EMSC program be funded at \$25 million in fiscal year 2008.

Although the administration proposes level funding for the hospital preparedness program, we are concerned with the \$13 million cut the program took in fiscal year 2007. All responders, providers and facilities must be ready to detect and respond to complex disasters, including terrorism, and HRSA must continue to support these vital hospital preparedness programs. Furthermore, HRSA's Trauma-EMS Systems Program, which is critical to ensure that our response to local, State and Federal emergencies is effective and reflects the best clinical practice in trauma and emergency medicine, was also proposed to be eliminated in fiscal year 2008. We request that the \$3.5 million funding level be restored.

The Office of Rural Health Policy, which serves more than 61 million people, was cut by 89 percent in the President's budget. Although almost a quarter of the U.S. population lives in rural areas, only an eighth of our doctors work there. Because rural families generally earn less than urban families, many health problems associated with poverty are more serious, including high rates of chronic disease and infant mortality. We encourage the subcommittee to restore funding for rural health programs. Additionally, the HRSA Rural and Community Access to Emergency Devices Program provides grants to States to train lay rescuers and first responders to use AEDs and purchase and place these devices in public areas where cardiac arrests are likely to occur. We encourage the subcommittee to restore funding for this program to the fiscal year 2005 level of \$8.927 million.

The HIV/AIDS Bureau received a \$21 million increase in the President's 2008 request over fiscal year 2007 levels for a total of \$2.1 billion. The Ryan White CARE Act programs are the largest single source of Federal discretionary funding for HIV/AIDS health care for low-income, uninsured and underinsured Americans. While we are pleased with the additional funds for HIV related drug therapies, it is insufficient to meet the needs of those seeking services. We are concerned that the cuts across the programs since fiscal year 2003 is diminishing the availability of services. These cuts have forced State, local and public health clinics' HIV/AIDS programs to stretch already thin dollars to treat existing clients while trying to provide care and treatment to those newly diagnosed. We request an increase of \$682 million for Ryan White programs in fiscal year 2008. In fiscal year 2006 the AIDS Drug Assistance Programs (ADAP) received a \$2 million increase. Unfortunately, by the end of fiscal year 2007 it is expected that hundreds more individuals will be added to ADAP waiting lists and that States will have had to institute other cost-containment measures such as reduced formularies, increased cost-sharing for ADAP clients and lowered eligibility requirements for enrollment.

Title X of the Public Health Service Act was enacted to provide high-quality, subsidized contraceptive care to those who cannot afford such services, to improve women's health, reduce unintended pregnancies, and decrease infant mortality and morbidity. Title X programs provide comprehensive, voluntary and affordable family planning services to millions—many of whom are uninsured—at more than 4,600 clinics nationwide. People who visit Title X funded clinics receive a broad package of preventive health services, including breast and cervical cancer screening, blood pressure checks, anemia testing, and STD/HIV screening.

A major source of HRSA's strength is its many linkages and partnerships with other Federal agencies, State, national and local organizations. For example, HRSA and the Centers for Medicare and Medicaid Services (CMS) are jointly implementing outreach on the new State Children's Health Insurance Program in addition to working together to improve data sharing and coordination, particularly on Medicaid. Work also is ongoing with the Substance Abuse and Mental Health Services Administration (SAMHSA) to integrate behavioral health and substance abuse screening, early intervention, referral and follow-up into primary health care settings funded through HRSA grants. HRSA and the Centers for Disease Control and Prevention (CDC) cooperate on a variety of disease prevention and health promotion activities.

We urge the members of the subcommittee to restore the allocations that were cut and fund the agency at a level that allows HRSA to effectively implement these important programs. The members of the Friends of HRSA are grateful for this opportunity to present our views to the subcommittee.

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#### PREPARED STATEMENT OF THE FRIENDS OF THE NIDA COALITION

Mr. Chairman and members of the subcommittee: The Friends of the National Institute on Drug Abuse (FoN), a burgeoning coalition of over 165 scientific and professional societies, patient groups, and other organizations committed to preventing and treating substance use disorders as well as understanding the causes and public health consequences of addiction, is pleased to provide testimony in support of the NIDA's extraordinary work. Pursuant to clause 2(g)4 of House Rule XI, the Coalition does not receive any Federal funds.

Drug abuse is costly—to individuals and to our society as a whole. Smoking, alcohol abuse and illegal drugs cost this country more than \$500 billion a year, with illicit drug use alone accounting for about \$180 billion in health care, crime, productivity loss, incarceration, and drug enforcement. Beyond its monetary impact, drug and alcohol abuse tear at the very fabric of our society, often spreading infectious diseases and bringing about family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. The good news is that treatment for drug abuse is effective and recovery from addiction is real for millions of Americans across the country. Preventing drug abuse and addiction and reducing these myriad adverse consequences is the ultimate aim of our Nation's investment in drug abuse research. Over the past three decades, scientific advances resulting from research have revolutionized our understanding of and approach to drug abuse and addiction.

Because of the critical importance of drug abuse research for the health and economy of our Nation, we write to you today to request your support for a 6.7 percent increase for NIDA in the fiscal year 2008 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. That would bring total funding for NIDA in fiscal year 2008 to \$1,067,389,455. Recognizing that so many health re-

search issues are inter-related, we also support a 6.7 percent increase for the National Institutes of Health overall, which would bring its total to \$30.8 billion for fiscal year 2008. This work deserves continuing, strong support from Congress. Below is a short list of significant NIDA accomplishments, challenges, and successes.

*Reducing Prescription Drug Abuse.*—NIDA research has documented a continued increase in the number of people, especially young people, who use prescription drugs for non-medical purposes. Particular concern revolves around the inappropriate use of opioid analgesics—very powerful pain medications. Research targeting a reduction in prescription drug abuse, particularly among our Nation's youth, should continue to be a priority for NIDA.

*Pain Medications and Addiction.*—FoN commends NIDA for taking a leadership role in addressing issues around pain medications and addiction. The most powerful treatments available for most forms of pain are opioids. However, opioid treatment can produce negative health consequences, such as intoxication and physical dependence, and may result in opioid abuse and addiction. The prevalence of and process of how to prevent, reduce, and treat, these negative health consequences in the context of pain are not well understood. FoN is pleased that NIDA brought a focus to this important issue, in collaboration with the American Medical Association and in conjunction with the NIH Pain Consortium, via its Spring 2007 conference "Pain, Opioids, and Addiction: An Urgent Problem for Doctors and Patients."

*Genes, Environment, and Development.*—FoN recognizes and commends NIDA for its leadership role in launching the Genes, Environment, and Development Initiative (GEDI) with the National Cancer Institute. This initiative will support research and add to our understanding of the contribution of genetic, environmental, and developmental factors to the etiology of substance abuse and related phenotypes, and will hopefully lead to improved and tailored drug abuse and addiction prevention and treatment interventions. FoN applauds this important, cutting-edge research.

*Social Neuroscience.*—Research-based knowledge about the dynamic interactions of genes with environment confirms addiction as a complex and chronic disease of the brain with many contributors to its expression in individuals. FoN applauds NIDA's involvement in last year's "social neuroscience" request for applications, and this year's "genes, environment, and development initiative" request for applications.

*Centers of Excellence for Physician Information.*—FoN is very pleased that NIDA has created Centers of Excellence for Physician Information, and understands that these Centers will serve as national models to support the advancement of addiction awareness, prevention, and treatment in primary care practices. The NIDA Centers of Excellence will target physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). FoN also applauds NIDA for developing these centers in collaboration with the American Medical Association's Research Education Consortium.

*Drug Abuse and HIV/AIDS.*—NIDA understands that drug abuse and addiction continue to fuel the spread of HIV/AIDS in the United States and abroad, and that drug abuse prevention and treatment interventions can be very effective in reducing HIV risk. Research should continue to examine every aspect of HIV/AIDS, drug abuse, and addiction, including risk behaviors associated with both injection and non-injection drug abuse, how drugs of abuse alter brain function and impair decision making, and HIV prevention and treatment strategies for diverse groups. FoN applauds the Institute for holding a Spring 2007 conference titled "Drug Abuse and Risky Behaviors: The Evolving Dynamics of HIV/AIDS."

*Medications Development.*—FoN commends NIDA for its continued leadership in working with private industry to develop anti-addiction medications and is pleased this collaboration resulted in an effective medication for opiate addiction. FoN encourages NIDA to continue its efforts to engage the private sector in the development of anti-addiction medications, particularly for cocaine, methamphetamine, and marijuana.

*Co-Occurring Disorders.*—NIDA recognizes that substance abuse is a disorder that can affect the course of many other diseases. To adequately address co-occurring health problems, FoN encourages the Institute to work with other agencies to stimulate new research to develop effective strategies and to ensure the timely adoption and implementation of evidence-based practices for the prevention and treatment of co-occurring disorders.

*Adolescent Brain Development—How Understanding the Brain Can Impact Prevention Efforts.*—FoN notes neuroimaging research by NIDA and others showing that the human brain does not fully develop until about age 25. This adds to the rationale for referring to addiction as a "developmental disease." FoN encourages NIDA to continue its emphasis on adolescent brain development to better under-

stand how developmental processes and outcomes are affected by drug exposure, the environment, and genetics.

*Translating Research Into Practice.*—FoN commends NIDA for its outreach and work with State substance abuse authorities to reduce the current 15- to 20-year lag between the discovery of an effective treatment intervention and its availability at the community level. In particular, FoN applauds NIDA for continuing its work with SAMHSA to strengthen State agencies' capacity to support and engage in research that will foster statewide adoption of meritorious science-based policies and practices. FoN encourages NIDA to continue this collaboration.

*Translational Research.*—Ensuring Research is Adaptable and Useable. FoN commends NIDA for its broad and varied information dissemination programs. FoN also understands that the Institute continues its focus on stimulating and supporting innovative research to determine the components necessary for adopting, adapting, delivering, and maintaining effective research-supported policies, programs, and practices. As evidence-based strategies are developed, FoN urges NIDA to support research to determine how these practices can be best implemented at the community level.

*Primary Care Settings and Youth.*—NIDA recognizes that primary care settings are potential key points of access to prevent and treat problem drug use among young people. FoN encourages NIDA to continue to support health services research on effective ways to educate primary care providers about drug abuse and develop brief behavioral interventions for preventing and treating drug use and related health problems; and develop methods to integrate drug abuse screening, assessment, prevention and treatment into primary health care settings.

*Utilizing Knowledge of Genetics and New Technological Advances to Curtail Addiction.*—NIDA recognizes that not everyone who takes drugs becomes addicted. Research has shown that genetics plays a critical role in addiction, and that the interplay between genetics and environment is crucial. FoN applauds the Institute's efforts to find new and important uses for brain imaging technologies and urges the Institute to continue work in this area.

*Reducing Health Disparities.*—NIDA research notes that the consequences of drug abuse disproportionately impact minorities, especially African American populations. FoN is pleased to learn that NIDA continues to encourage researchers to conduct more studies in this population and to target their studies in geographic areas where HIV/AIDS is high and or growing among African Americans, including in criminal justice settings.

*The Clinical Trials Network—Using Infrastructure to Improve Health.*—FoN is pleased with the continued success and progress of NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN). The CTN provides an infrastructure to test the effectiveness of new and improved interventions in real-life community settings with diverse populations, enabling an expansion of treatment options for providers and patients.

*Drug Treatment in Criminal Justice Settings.*—NIDA is very concerned about the well-known connections between drug use and crime. Research continues to demonstrate that providing treatment to individuals involved in the criminal justice system significantly decreases future drug use and criminal behavior, while improving social functioning. FoN strongly supports NIDA's efforts in this area, particularly the Criminal Justice Drug Abuse Treatment Studies (CJ-DATS).

*Emerging Drug Problems.*—FoN recognizes that drug use patterns are constantly changing and is pleased with NIDA's efforts to monitor drug use trends and to rapidly inform the public of emerging drug problems. FoN especially encourages NIDA to continue supporting research that provides reliable data on emerging drug trends, particularly among youth and in major U.S. cities.

*Reducing Methamphetamine Abuse.*—NIDA is very concerned about the continued abuse of methamphetamine across the United States. NIDA notes the advances in understanding methamphetamine abuse and addiction, and is encouraged by the growing evidence of treatment effectiveness in these populations. FoN urges NIDA to continue supporting research to address the broad medical consequences of methamphetamine abuse.

*Reducing Inhalant Abuse.*—NIDA understands and is alarmed that inhalant use continues to be a significant problem among our youth. FoN urges the Institute to continue its support of research on prevention and treatment of inhalant abuse, and to enhance public awareness on this issue.

*Long-Term Consequences of Marijuana Use.*—NIDA is concerned with the continuing widespread use of marijuana. FoN urges NIDA to continue support for efforts to assess the long-term consequences of marijuana use on cognitive abilities, achievement, and mental and physical health, as well as work with the private sector to develop medications focusing on marijuana addiction.

*Blending Research and Practice.*—NIDA notes that it takes far too long for clinical research results to be implemented as part of routine patient care, and that this lag in diffusion of innovation is costly for society, devastating for individuals and families, and wasteful of knowledge and investments made to improve the health and quality of people's lives. FoN applauds NIDA's collaborative approach aimed at proactively involving all entities invested in changing the system and making it work better.

*Disseminating Drug Abuse and Addiction Research Information to the General Public.*—FoN congratulates NIDA for its collaboration with HBO and other partners on the production of a groundbreaking documentary film on addiction. This film details the latest scientific knowledge on addiction and presents it in a compelling way for the lay public, helping people to understand addiction as a brain disease that can be successfully treated. FoN recognizes the importance of this documentary because it shows that substance abuse happens to ordinary, every day people, and that treatment can be very successful. The documentary should encourage support of those who suffer from this disease, and will reduce the stigma that so often accompanies it.

*Support for Young Investigators.*—NIDA recognizes the importance of, over time, replenishing the "pipeline" of researchers in the addiction field. FoN congratulates NIDA for its focus on supporting young investigators, especially in the area of clinical research. Such support is crucial to the future of this field, and the Institute should continue its efforts in this area.

Thank you, Mr. Chairman, and the subcommittee, for your support for the National Institute on Drug Abuse.

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#### PREPARED STATEMENT OF GALLAUDET UNIVERSITY

Mr. Chairman and members of the committee: I would like to express my appreciation to you and to Congress for the generous support that we received in fiscal year 2007 during what I know are difficult times for Federal funding. I am especially grateful that Congress continues to support us during these challenging times, and I am writing in support of our appropriation request for fiscal year 2008. As I enter the first months of my presidency, I would like to introduce myself to you and discuss briefly the challenges that Gallaudet has faced during the past year and those that it will face in the near future.

In December, 2006, I was appointed interim president of Gallaudet following a lengthy protest, involving a broad segment of the Gallaudet community, against the installation of the individual appointed by Gallaudet's Board of Trustees to succeed Dr. I. King Jordan. I recently informed the University community that the 2 months since I took office on January 2, 2007 have been the most difficult and challenging of my 50 year career in education and government service (I have come out of retirement for a second time to accept this challenge). At the same time, this may be the most energized I have ever felt, as well. I do not want to minimize the seriousness of the issues that were at the heart of the protest, but I also want to assure you that I believe the Gallaudet community has never been more unified in its purpose to work together toward a future that will be worthy of Gallaudet's distinguished past.

First though, I think it is important for you to know something about the qualifications I bring to this task. I am a proud graduate of Gallaudet, having received my bachelor's degree in 1953. As I have told everyone willing to listen to my story, it was Gallaudet that prepared me to take advantage of the opportunities that eventually became open to me—Gallaudet made me what I am, and like many other deaf people I will always be grateful for that. When I left Gallaudet, I became a mathematics teacher at the New York School for the Deaf in White Plains. After earning a Master's degree from Hunter College and a Ph.D. in educational technology from Syracuse University, I was appointed director of the Kendall Demonstration Elementary School and then vice president for Pre-College Programs at Gallaudet.

Following 11 years as a Gallaudet vice president, I was appointed by President George H. W. Bush and approved by the Senate as Assistant Secretary of Education for Special Education and Rehabilitative Services, where I served as the chief oversight officer for Gallaudet and the National Technical Institute for the Deaf (NTID) until 1993. Since then, I have served for 3 years as headmaster of the New York School and, finally, for 8 years as vice president of the Rochester Institute of Technology and director of NTID. I think my career experiences have given me a unique perspective on the needs of Gallaudet University and on its relationship with the Federal Government.

I would like to address those needs briefly. Because of Congress's support for Gallaudet during recent years, we have been able to maintain a competitive pay structure for our employees while retaining the flexibility to meet the needs of a changing student body. Given the unique student population we serve and the communication skills our employees are expected to possess, retaining skilled employees is critical to our mission. Gallaudet employees received general pay increases of 2 percent in fiscal year 2003, 3 percent in fiscal year 2004, 2 percent in fiscal year 2005, and 2 percent again in fiscal year 2006 and 2007, increases that are below what Federal employees in the region received during the same timeframe, and somewhat below increases in the Consumer Price Index (CPI). During the most recent 12 month period, the national CPI-U increased by 2.1 percent and that for the Washington, DC locality increased by 2.9 percent. Given these current rates of inflation and a small erosion in the purchasing power of our employee salaries in recent years, I am projecting the need for a 3 percent general pay increase in fiscal year 2008. We are also requesting support for inflationary increases in non-salary areas, especially in the cost of utilities and benefits. In this regard, I need to point out that our benefits costs during the past several years have increased by more than 2 percent of base salaries, and we have had to fund those increases as part of our total payroll package.

The administration budget for fiscal year 2008 includes \$106.998 million for Gallaudet, the same as our fiscal year 2007 and 2006 appropriations, and it would, thus, represent a second year of no funding increase. Moreover, the administration budget proposes that \$600,000 of that base budget be used by the Department of Education for a major evaluation of Gallaudet's programs. As a former Federal oversight officer for Gallaudet, I understand the importance of evaluation studies, and I would welcome working in this way with the Federal Government, but I need to point out that taking these funds from our existing budget would further erode our financial base. I have carefully analyzed our fiscal year 2008 funding needs and have determined that in order to provide a 3 percent salary increase to our faculty and staff, and to meet other inflation-driven increases, we need an increase of at least 3 percent, or \$3.2 million, in our appropriation for operations. I have announced a set of priorities to the Gallaudet community that are student centered and that are designed to restore Gallaudet's traditional reputation for excellence in the education of deaf students. This modest increase in our appropriation would provide substantial support for the achievement of this agenda.

In addition, I want to bring to your attention a major problem for Gallaudet's infrastructure. During the past several years, there has been damage to dormitories serving the students of the Model Secondary School for the Deaf (MSSD) as a result of instability in the hillside site of the school's facilities. This instability is due to the construction of the facilities on an area underlain by a layer of marine clay, a problem that has been identified throughout the Washington region only during the past 20 to 30 years, following the construction of the MSSD facilities. We have discussed this problem with officials from the Department of Education in the past, but only with respect to the dormitories. During the past year, it has become evident that the main MSSD academic building is now being affected and there are threats to other buildings in the vicinity, including the Kendall Demonstration Elementary School (KDES). We have retained soil and structural engineers to assist us in assessing the current damage and the future threat, and to help us estimate costs for stabilizing the site and repairing the structural damage that has already occurred. Because of the urgent nature of the situation we have sought the support of the Department and are requesting funding to begin site stabilization from Congress in fiscal year 2008. Current estimates for stabilizing the site and repairing the existing damage are in the range of \$15 to \$20 million. I am requesting \$7.5 million in fiscal year 2008 to support the cost of stabilizing the site. I will be making further requests to repair the damage to facilities in fiscal year 2009.

In making this request, I want to point out that Gallaudet has not asked for special funding for construction for many years. The buildings most recently constructed on the campus, the Kellogg Conference Center and the Jordan Student Academic Center were constructed with privately raised funds, as will be the Sorenson Center for Language and Communication that is currently under construction. So, I do not make this request lightly. The Model Secondary School is operated as a public school, without charging tuition and with the full support of the Federal Government. Therefore, I believe this request for support is both prudent and appropriate.

## FUNDING REQUEST FOR FISCAL YEAR 2008

In our budget request to the Department of Education for fiscal year 2008, we addressed the need for inflationary increases as well as support for program development. Given the funding issues currently facing Congress, I am requesting support at this time only for our most pressing inflationary needs and the need to address the infrastructure issues I described above. Funding of our need to cover inflationary costs will provide us some budget stability, but we will continue to face the need for development and enhancement of our programs. Our strategy will be to seek alternative sources of funding for some of these program priorities and to defer development of others. We will continue to seek support for program growth from both Federal and private sources in the future.

—Inflationary costs at 3 percent—\$3.2 million.

—MSSD site stabilization—\$7.5 million.

My total request for fiscal year 2008 is, thus, \$117.7 million; \$110.2 million for operations and \$7.5 million for site stabilization of the MSSD facilities.

I appreciate the challenges that Congress faces in making appropriations decisions for fiscal year 2008, but I believe experience has shown that Gallaudet provides an outstanding return on Federal dollars that are invested here, in terms of the educated and productive deaf community that the Nation enjoys as a result. Thank you.

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PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION  
COALITION

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record in support of the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act. HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and others dedicated to ensuring that Title VII and VIII programs continue to help educate the Nation's health care and public health personnel. HPNEC members are thankful for the support the subcommittee has provided to the programs, which are essential to building a well-educated, diverse health care workforce.

The Title VII and VIII health professions and nursing programs are essential components of the Nation's health care safety net, bringing health care services to underserved communities. These programs support the training and education of health care providers with the aim of enhancing the supply, diversity, and distribution of the workforce, filling the gaps in the health professions' supply not met by traditional market forces. The Title VII and VIII health professions programs are the only Federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

The final fiscal year 2006 Labor-HHS-Education Appropriations bill cut Title VII & VIII programs by 34.5 percent, including a 51.5 percent cut to Title VII programs. The \$40 million increase provided for Title VII in the recently enacted fiscal year 2007 joint funding resolution does not restore these devastating cuts. Moreover, the President's fiscal year 2008 budget proposes an additional 94.6 percent cut to Title VII and a 29.7 percent cut to Title VIII.

HPNEC members recommend that the Title VII and VIII programs receive an appropriation of at least \$550 million for fiscal year 2008. This recommendation would ensure the programs have sufficient funds to continue fulfilling their mission of educating and training a health care workforce that meets the public's health care needs.

During their 40-year existence, the Title VII and VIII programs have created a network of initiatives across the country that supports the training of many disciplines of health providers. Together, the programs work in concert with the National Health Service Corps and Community Health Centers (CHCs) to strengthen the health safety net for rural and medically underserved communities. A March 2006 study published in the *Journal of the American Medical Association (JAMA)* found that CHCs report high percentages of provider vacancies, including an insufficient supply of dentists, pharmacists, pediatricians, family physicians, and registered nurses; these shortages are especially pronounced in rural areas. Because Title VII and VIII programs have a successful record of training providers who serve underserved areas, the study recommends increased support for the programs as its primary means of alleviating the shortages. Further, the study serves as an important reminder that the success of CHCs is highly dependent upon a well-trained clinical staff to provide care.

HPNEC members urge the subcommittee to consider the vital need for these health professions education programs as demonstrated by the passage of the Health Professions Education Partnerships Act of 1998 (Public Law 105-392), which reauthorized the programs. The reauthorization consolidated the programs into seven general categories:

- The purpose of the Minority and Disadvantaged Health Professionals Training programs is to improve health care access in underserved areas and the representation of minority and disadvantaged health care providers in the health professions. Minority Centers of Excellence support programs that seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The Health Career Opportunity Program seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The Faculty Loan Repayment and Faculty Fellowship programs provide incentives for schools to recruit underrepresented minority faculty. The Scholarships for Disadvantaged Students (SDS) make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students.
- The Primary Care Training category, including General Pediatrics, General Internal Medicine, Family Medicine, General Dentistry, Pediatric Dentistry, and Physician Assistants, provides for the education and training of primary care physicians, dentists, and physician assistants to improve access and quality of health care in underserved areas. The General Pediatrics, General Internal Medicine, and Family Medicine programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. The General Dentistry and Pediatric Dentistry programs provide grants to dental schools and hospitals to create or expand primary care dental residency training programs. Recognizing that all primary care is not only provided by physicians, the primary care cluster also provides grants for Physician Assistant programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. Additionally, these programs enhance the efforts of osteopathic medical schools to continue to emphasize primary care medicine, health promotion, and disease prevention, and the practice of ambulatory medicine in community-based settings.
- Because much of the Nation's health care is delivered in areas far removed from health professions schools, the Interdisciplinary, Community-Based Linkages cluster provides support for community-based training of various health professionals. These programs are designed to provide greater flexibility in training and to encourage collaboration between two or more disciplines. These training programs also serve to encourage health professionals to return to such settings after completing their training. The Area Health Education Centers (AHECs) provide clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. Health Education and Training Centers (HETCs) were created to improve the supply of health professionals along the U.S.-Mexico border. They incorporate a strong emphasis on wellness through public health education activities for disadvantaged populations. Geriatric Health Professions programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, which are all designed to bolster the number and quality of health care providers caring for our older generations. The Quentin N. Burdick Program for Rural Health Interdisciplinary Training places an emphasis on long-term collaboration between academic institutions, rural health care agencies and providers to improve the recruitment and retention of health professionals in rural areas. The Allied Health Project Grants program represents the only Federal effort aimed at supporting new and innovative education programs designed to reduce shortages of allied health professionals and create opportunities in medically underserved and minority areas. The Graduate Psychology Education Program provides grants to doctoral, internship and postdoctoral programs in support of interdisciplinary training of psychology students with other health professionals for the provision of mental and behavioral health services to underserved populations, especially in rural and urban communities.
- The Health Professions Workforce and Analysis program provides grants to institutions to collect and analyze data on the health professions workforce to ad-

vises future decision-making on the direction of health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed a number of valuable, policy-relevant studies on the distribution and training of health professionals, including the Eighth National Sample Survey of Registered Nurses (NSSRN), the Nation's most extensive and comprehensive source of statistics on registered nurses.

- The Public Health Workforce Development programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. Preventive Medicine Residencies provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. Dental Public Health Residency programs are vital to the Nation's dental public health infrastructure. The Health Administration Traineeships and Special Projects grants are the only Federal funding provided to train the managers of our health care system, with a special emphasis on those who serve in underserved areas.
- The Nursing Workforce Development programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. Health care entities across the Nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and capacity limitations within the educational system. Each year, nursing schools turn away between 42,000 and 92,000 qualified applicants at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Congress responded to this dire national need by passing the Nurse Reinvestment Act (Public Law 107-205) in 2002, which increases nursing education, retention, and recruitment. The Advanced Education Nursing program awards grants to train a variety of advanced practice nurses, including nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. Workforce Diversity grants support opportunities for nursing education for disadvantaged students through scholarships, stipends, and retention activities. Nurse Education, Practice, and Retention grants are awarded to help schools of nursing, academic health centers, nurse managed health centers, State, and local governments, and other health care facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The Loan Repayment and Scholarship Program repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds. In return these students are required to work for at least 2 years of practice in a designated nursing shortage area. The Comprehensive Geriatric Education grants are used to train RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, train faculty members, and provide continuing education. The Nurse Faculty Loan program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty. The Title VIII nursing programs also support the National Advisory Council on Nurse Education and Practice, which is charged with advising the Secretary of Health and Human Services and Congress on nursing workforce, education, and practice improvement issues.
- The loan programs in the Student Financial Assistance support needy and disadvantaged medical and nursing school students in covering the costs of their education. The Nursing Student Loan (NSL) program provides loans to undergraduate and graduate nursing students with a preference for those with the greatest financial need. The Primary Care Loan (PCL) program provides loans covering the cost of attendance in return for dedicated service in primary care. The Health Professional Student Loan (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The NSL, PCL, and HPSL programs are funded out of each institution's revolving fund and do not receive Federal appropriations. The Loans for Disadvantaged Students (LDS) program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

These programs work collectively to fulfill their unique, three-pronged mission:

*Title VII & VIII programs enhance the supply of the health professions workforce*

A network of 50 Geriatric Education Centers has trained over 500,000 health practitioners in 35 health-related disciplines to better serve the burgeoning elderly population.

As the largest source of Federal funding for nursing education, the Nursing Workforce Development programs provided loan, scholarship, and programmatic support to 48,698 student nurses and nurses in fiscal year 2006.

*Title VII & VIII programs improve the distribution of health care providers*

A study published in the Winter 2006 issue of the Journal of Rural Health reports that up to 83 percent of family medicine residents and 80 percent of nurse practitioners who went through a program with Title VII or VIII funding chose to practice in areas with health professions shortages or medically underserved practice locations.

A study from the University of California, San Francisco shows that medical schools that receive primary care training dollars produce more physicians who work in CHCs and serve in the National Health Service Corps compared to schools without Title VII primary care funding.

*Title VII & VIII programs increase the representation of minority and disadvantaged students in the health professions*

A study published in the September 2006 issue of the JAMA finds that post-baccalaureate programs, which rely on Title VII among other sources of funding, are highly effective in increasing minority representation in medical school. The study concludes that enacted reductions in funding for Title VII may have negative consequences for these effective programs.

A review of physician assistant graduates from 1990–2004 reveals that graduates of Title VII supported programs were 67 percent more likely to be from underrepresented minority backgrounds than graduates of non-Title VII supported programs.

HPNEC members respectfully urge support for funding of at least \$550 million for the Title VII and VIII programs, an investment essential not only to the development and training of tomorrow's health care professions but also to our Nation's efforts to provide needed health care services to underserved and minority communities. We greatly appreciate the support of the subcommittee and look forward to working with Members of Congress to achieve these goals in fiscal year 2008 and into the future.

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PREPARED STATEMENT OF THE HEART RHYTHM SOCIETY

The Heart Rhythm Society (HRS) thanks you and the Subcommittee on Labor, Health and Human Services and Education for your past and continued support of the National Institute of Health, and specifically the National Heart, Lung and Blood Institute (NHLBI).

The Heart Rhythm Society, founded in 1979 to address the scarcity of information about the diagnosis and treatment of cardiac arrhythmias, is the international leader in science, education and advocacy for cardiac arrhythmia professionals and patients, and the primary information resource on heart rhythm disorders. The Heart Rhythm Society serves as an advocate for millions of American citizens from all 50 States, since arrhythmias are the leading cause of heart-disease related deaths. Other, less lethal forms of arrhythmias are even more prevalent, account for 14 percent of all hospitalizations of Medicare beneficiaries.<sup>1</sup> Our mission is to improve the care of patients by promoting research, education and optimal health care policies and standards. We are the preeminent professional group, representing more than 4,200 specialists in cardiac pacing and electrophysiology.

The Heart Rhythm Society recommends the subcommittee renew its commitment to supporting biomedical research in the United States and recommends Congress provide NIH with a 6.7 percent increase for fiscal year 2008. This increase will enable NIH and NHLBI to sustain the level of research that leads to research breakthroughs and improved health outcomes. In particular, the Heart Rhythm Society recommends Congress support research into abnormal rhythms of the heart.

HRS appreciates the actions of Congress to double the budget of the NIH in recent years. The doubling has directly promoted innovations that have improved treatments and cures for a myriad of medical problems facing our Nation. Medical research is a long-term process and in order to continue to meet the evolving chal-

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<sup>1</sup>Heart Rhythm Foundation, Arrhythmia Key Facts, 2004 <http://www.heartrhythmfoundation.org/facts/arrhythmia.asp>

lenges of improving human health we must not let our commitment wane. Furthermore, NIH research fuels innovation that generates economic growth and preserves our Nation's role as a world leader in the biomedical and biotech industries. Healthier citizens are the key to robust economic growth and greater productivity. Economists estimate that improvements in health from 1970 to 2000 were worth \$95 trillion. During the same time period, the United States invested \$200 billion in the NIH. If only 10 percent of the overall health savings resulted from NIH-funded research, our investment in medical research has provided a 50-fold return to the economy.<sup>2</sup>

Unfortunately, since the end of the doubling in 2003, funding for NIH has failed to keep pace with biomedical inflation. As a result 13 percent of NIH's purchasing power has been lost. Because of this NIH has been unable to fully fund existing multi-year grants, thus stalling life-saving discoveries. If these vacillations in funding continue, future generations of researchers will become discouraged from pursuing a career in basic science and laboratories' resources could be strained to the point of forcing lay-offs and even closure.

#### RESEARCH ACCOMPLISHMENTS

In the field of cardiac arrhythmias, NIH-funded research has advanced our ability to treat atrial fibrillation and thus prevent the devastating complications of stroke. Atrial fibrillation is found in about 2.2 million Americans and increases the risk for stroke about 5-fold. About 15–20 percent of strokes occur in people with atrial fibrillation. Stroke is a leading cause of serious, long-term disability in the United States and people who have strokes caused by AF have been reported as 2–3 times more likely to be bedridden compared to those who have strokes from other causes. Each year about 700,000 people experience a new or recurrent stroke and in 2002 stroke accounted for more than 1 of every 15 deaths in the United States. Ablation therapy however is providing a cure for individuals whose rapid heart rates had previously incapacitated them, giving them a new lease on life.<sup>3</sup>

Important advances have also been made in identifying patients with heart failure and those who have suffered a heart attack and are at risk for sudden death. The development, through initial NIH-sponsored research, and implantation of sophisticated internal cardioverter defibrillators (ICD's) in such patients has saved the lives of hundreds of thousands and provides peace of mind for families everywhere, including that of Vice-President Cheney's. A new generation of pacemakers and ICDs is restoring the beat of the heart as we grow older, permitting us to lead more normal and productive lives, reducing the burden on our families, communities and the healthcare system. Arrhythmias and sudden death affect all age groups and are not solely diseases of the elderly.

Research advances in molecular genetics have provided us the root basis for life-threatening abnormal rhythms of the heart associated with a wide range of inherited syndromes including long and short QT, Brugada syndromes, and hypertrophic cardiomyopathies. Inroads have been achieved in the identification of cardiac arrhythmias as a cause of Sudden Infant Death Syndrome (SIDS) and the genetic basis for a new clinical entity associated with sudden death of young adults was uncovered earlier this year. This knowledge has provided guidance to physicians for better detection and treatment of these sudden death syndromes reducing mortality and disability of infants, children and young adults. Individuals who survive an instance of sudden death often remain in vegetative states, resulting in a devastating burden on their families and an enormous economic burden on society. These advances have translated into sizeable savings to the health care system in the United States. Researchers are also developing a noninvasive imaging modality for cardiac arrhythmias. Despite the fact that more than 325,000 Americans die every year from heart rhythm disorders, a noninvasive imaging approach to diagnosis and guided therapy of arrhythmias, the equivalent of CT or MRI, has previously not been available.

The NIH-funded Public Access Defibrillation (PAD) Trial was also able to determine that trained community volunteers increase survival for victims of cardiac arrest. It had already been known that defibrillation, utilizing an automated external defibrillator (AED), by trained public safety and emergency medical services personnel is a highly effective live-saving treatment for cardiac arrest. A NIH-funded

<sup>2</sup>Murphy, KM and Topel, RH, The Value of Health and Longevity, National Bureau of Economic Research Working Paper Series, Working Paper 11405, June 2005.

<sup>3</sup>American Stroke Association and American Heart Association, Heart Disease and Stroke Statistics 2005 Update, 2005 <http://www.americanheart.org/downloadable/heart/1105390918119HDSStats2005Update.pdf>

trial however was able to conclude that placing AED's in public places and training lay persons to use them can prevent additional deaths and disabilities.<sup>4</sup>

Without NIH support, these life-saving findings may have taken a decade to unravel. The highly focused approach utilizing basic and clinical expertise, funded through Federal programs made these advances a reality in a much shorter time-period.

#### BUDGET JUSTIFICATION

These impressive strides notwithstanding, cardiac arrhythmias continue to plague our society and take the lives of loved ones at all ages, nearly one every minute of every day, as well as straining an already burdened health system. Sudden Cardiac Arrest is a leading cause of death in the United States, claiming an estimated 325,000 lives every year, or one life every 2 minutes.<sup>5</sup> The burden of morbidity and mortality due to cardiac arrhythmias is predicted to grow dramatically as the baby boomers age. Atrial fibrillation strikes 3–5 percent of people over the age of 65,<sup>6</sup> Apresenting a skyrocketing economic burden to our society in the form of healthcare treatment and delivery. Cardiac diseases of all forms increase with advancing age, ultimately leading to the development of arrhythmias. Effective drug therapy for the management of atrial fibrillation is one of the greatest unmet needs in our society today and additional research is needed to address this problem. NIH research provides the basis for the medical advances that hold the key to lowering health care costs.

The above progress we have witnessed in recent years will provide treatments for this illness, only if the resources continue to be available to the academic scientific and medical community. However, the budgets appropriated by Congress to the NIH in the past 3 years were far below the level of scientific inflation. These vacillations in funding cycles threaten the continuity of the research and the momentum that has been gained over the years. While HRS recognizes that Congress must balance other priorities, sustaining multi-year growth for the biomedical research enterprise is critical. A central objective of the doubling of the NIH budget was to accelerate solutions to human disease and disability. NIH is now engaging in the next generation of biomedical research to translate basic research and clinical evidence into new cures. Our ability to bring together uniquely qualified and devoted investigators and collaborators both at the basic science level and in the clinical arena is a vital key to our to this success. Funding models however show that a threshold exists, below which NIH will not be able to maintain its current scope and number of grants, let alone expand its programs to address new concerns and emerging opportunities. Furthermore, the United States is in danger of losing its leadership role in science and technology. The United States faces growing competition from other nations, such as China and India, which are working to invest more of their GDP's into building state-of-the art research institutes and universities to foster innovation and compete directly for the world's top students and researchers.<sup>7</sup>

It is for this reason that we are asking for your support to increase NIH appropriations by 6.7 percent for fiscal year 2008. The Heart Rhythm Society recommends Congress specifically acknowledge the need for cardiac arrhythmia research to prevent sudden cardiac arrest and other life threatening conditions such as sudden infant death syndrome, definitive therapeutic approaches for atrial fibrillation and the prevention of stroke, and other genetic arrhythmia conditions. Thank you very much for your consideration of our request.

If you have any questions or need additional information, please contact Nevena Minor, Coordinator, Health Policy at the Heart Rhythm Society (nminor@hrsonline.org or 202-464-3431).

Thank you again for the opportunity to submit testimony.

<sup>4</sup>National Heart Lung and Blood Institute, NIH, Public Access Defibrillation by Trained Community Volunteers Increases Survival for Victims of Cardiac Arrest, November 2003 <http://www.nhlbi.nih.gov/new/press/03-11-11.htm>

<sup>5</sup>Heart Rhythm Foundation, The Facts on Sudden Cardiac Arrest, 2004 <http://www.heartrhythmfoundation.org/itsabouttime/pdf/providerfactsheet.pdf>

<sup>6</sup>Heart Rhythm Society, Atrial Fibrillation & Flutter, 2005 <http://www.hrspatients.org/patients/heart-disorders/atrial-fibrillation/default.asp>

<sup>7</sup>Task Force on the Future of American Innovation, The Knowledge Economy: Is the United States Losing it's Competitive Edge?, February 16, 2005.

## PREPARED STATEMENT OF THE HEPATITIS FOUNDATION INTERNATIONAL

## SUMMARY OF FISCAL YEAR 2007 RECOMMENDATIONS

Continue the great strides in research at the National Institutes of Health (NIH) by providing a 6.7 percent budget increase for fiscal year 2008. Increase funding for the National Institute for Allergy and Infectious Diseases (NIAID), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA) by 6.7 percent.

Continued support for the hepatitis B vaccination program for adults at the Centers for Disease Control and Prevention (CDC) as well as CDC's Prevention Research Centers by providing an 8 percent increase for CDC.

Support for the Substance Abuse and Mental Health Services Administration (SAMHSA) by providing an 8 percent increase in fiscal year 2007.

Urge CDC, NIAID, NIDDK, NIAAA, NIDA, and SAMHSA to work with voluntary health organizations to promote liver wellness, education, and prevention of both hepatitis and substance abuse.

Mr. Chairman and members of the subcommittee, thank you for your continued leadership in promoting better research, prevention, education, and control of diseases affecting the health of our Nation. I am Thelma King Thiel, Chairman and Chief Executive Officer of the Hepatitis Foundation International (HFI).

Currently, five types of viral hepatitis have been identified, ranging from type A to type E. All of these viruses cause acute, or short-term, viral hepatitis. Hepatitis B, C, and D viruses can also cause chronic hepatitis, in which the infection is prolonged, sometimes lifelong. While treatment options are available for many patients, individuals with chronic viral hepatitis B and C represent a significant number of the patients that require a liver transplant. Current treatments have limited success and there is no vaccine available for hepatitis C, the most prevalent of these diseases.

## HEPATITIS B

Hepatitis B (HBV) claims an estimated 5,000 lives every year in the United States, even though therapies exist that slow the progression of liver damage. Vaccines are available to prevent hepatitis B. This disease is spread through contact with the blood and body fluids of an infected individual and from an HBV infected mother to child at birth. Unfortunately, due to both a lack in funding to vaccinate adults and the absence of an integrated preventive education strategy, transmission of hepatitis B continues to be problematic. Additionally, there are significant disparities in the occurrence of chronic HBV-infections. For example, Asian Americans represent 4 percent of the population; however, they account for more than half of the 1.3 million chronic hepatitis B cases in the United States. Current treatments do not cure hepatitis B, but appropriate treatment can help to reduce the progression to liver cancer and liver failure. Yet, many are not treated. Preventive education and universal vaccination are the best defenses against hepatitis B.

HFI supports the recommendation to increase funding by \$50 million for the cost of vaccines for adults offered by the Institute of Medicine in their report, entitled "Calling the Shots: Immunization Finance Policies and Practices."

## HEPATITIS C

Infection rates for hepatitis C (HCV) are at epidemic proportions. Unfortunately, many individuals are not aware of their infection until many years after they are infected. This creates a dangerous situation, as individuals who are infected unknowingly continue to spread the disease. The Center for Disease Control and Prevention estimates that there are over 4 million Americans who have been infected with hepatitis C, of which over 2.7 million remain chronically infected, with 8,000–10,000 deaths each year. Additionally, the death rate is expected to triple by 2010 unless additional steps are taken to improve outreach and education on the prevention of hepatitis C and scientists identify more effective treatments and cures. As there is no vaccine for HCV, prevention education and treatment of those who are infected serve as the most effective approach in halting the spread of this disease.

## PREVENTION IS THE KEY

The absence of information about the liver and hepatitis in education programs over the years has been a major factor in the spread of viral hepatitis through unknowing participation in liver damaging activities. Adults and children need to understand the importance of the liver and how viruses and drugs can damage its abil-

ity to keep them alive and healthy. Many who are currently infected are unaware of the risks they are taking that expose them to viral infections and ultimately liver damage.

Knowledge is the key to prevention. Preventive education is essential to motivate individuals to protect themselves and avoid behaviors that can cause life-threatening diseases. Primary prevention that encourages individuals to adopt healthful lifestyle behaviors must begin in elementary schools when children are receptive to learning about their bodies. In addition to educating individuals at a critical age, schools provide access to one-fifth of the American population.

Individuals need to be motivated to assess their own risk behaviors, to seek testing, to accept vaccination, to avoid spreading their disease to others, and to understand the importance of participating in their own health care and disease management. The NIH needs to support education programs to train teachers and healthcare providers in effective communication techniques, and to evaluate the impact preventive education has on reducing the incidence of hepatitis and substance abuse.

Therefore, HFI recommends that CDC, NIAID, NIDDK, NIAAA, NIDA, and SAMHSA be urged to work with voluntary health organizations to promote liver wellness, education, and prevention of viral hepatitis, sexually transmitted diseases and substance abuse.

Only a major investment in immunization and preventive education will bring these diseases under control. All newborns, young children, young adults, and especially those who participate in high-risk behaviors must be a priority for immunization, outreach initiatives, and preventive education. We recommend that the following activities be undertaken to prevent the further spread of all types of hepatitis:

- Provide effective preventive education in our elementary and secondary schools so children can avoid the serious health consequences of risky behaviors that can lead to viral hepatitis.
- Train educators, health care professionals, and substance abuse counselors in effective communication and counseling techniques.
- Promote public awareness campaigns to alert individuals to assess their own risk behaviors, motivate them to seek medical advice, encourage immunization against hepatitis A and B, and to stop the consumption of any alcohol if they have participated in risky behaviors that may have exposed them to hepatitis C.
- Expand screening, referral services, medical management, counseling, and prevention education for individuals who have HCV, many of whom may be co-infected with HIV and Hepatitis C and/or Hepatitis B.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

HFI recommends an increase of \$12 million in fiscal year 2008 for further implementation of CDC's Hepatitis C Prevention Strategy. Such an increase would bring the total funding level for the Hepatitis C Prevention Strategy to \$30 million in fiscal year 2008. This increase will support and expand the development of state-based prevention programs by increasing the number of State health departments with CDC funded hepatitis coordinators. The Strategy will use the most cost-effective way to implement demonstration projects evaluating how to integrate hepatitis C and hepatitis B prevention efforts into existing public health programs.

CDC's Prevention Research Centers, an extramural research program, plays a critical role in reducing the human and economic costs of disease. Currently, CDC funds 26 prevention research centers at schools of public health and schools of medicine across the country. HFI encourages the subcommittee to increase core funding for these prevention centers, as it has been decreasing since this program was first funded in 1986. We recommend the subcommittee provide an 8 percent increase for the Prevention Research Centers program in fiscal year 2008.

Also, HFI recommends that the CDC, particularly the Division of Adolescent and School Health (DASH), work with voluntary health organizations to promote liver wellness with increased attention toward childhood education and prevention, especially through partnerships between school districts and non-governmental organizations.

#### INVESTMENTS IN RESEARCH

Investment in the NIH has led to an explosion of knowledge that has advanced understanding of the biological basis of disease and development of strategies for disease prevention, diagnosis, treatment, and cures. Countless medical advances have directly benefited the lives of all Americans. NIH-supported scientists remain

our best hope for sustaining momentum in pursuit of scientific opportunities and new health challenges. For example, research into why some HCV infected individuals resolve their infection spontaneously may prove to be life saving information for others currently infected. Other areas that need to be addressed are:

- Reasons why African Americans do not respond as well as Caucasians and Hispanics to antiviral agents in the treatment of chronic hepatitis C.
- Pediatric liver diseases, including viral hepatitis.
- The outcomes and treatment of renal dialysis patients who are infected with HCV and HBV.
- Co-infections of HIV/HCV and HIV/HBV positive patients.
- Hemophilia patients who are co-infected with HIV/HCV and HIV/HBV.
- The development of effective treatment programs to prevent recurrence of HCV infection following liver transplantation.
- The development of effective vaccines to prevent HCV infection.

HFI supports a 6.7 percent increase for NIH in fiscal year 2008. HFI also recommends a comparable increase of 6.7 percent in hepatitis research funding at NIAID, NIDDK, NIAAA, and NIDA.

HFI is dedicated to the eradication of viral hepatitis, which affects over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle. Thank you for providing this opportunity to present testimony.

#### PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America represents more than 3,600 physicians, scientists and other health care professionals who practice on the frontline of the HIV/AIDS pandemic. Our members treat people with HIV/AIDS throughout the United States and the world, develop and implement effective prevention interventions, and conduct research to develop effective prevention technologies, effective vaccines and less complex and less toxic treatment regimens for use in the United States and abroad. They are medical providers that specialize in HIV medicine and work in communities across the country and in more than 150 countries outside of the United States.

The United States must sustain our three-pronged response to the AIDS pandemic—conducting research to effectively prevent and treat HIV disease; supporting programs that identify persons infected with HIV and prevent or reduce HIV transmission; and providing access to lifesaving HIV treatment to people without a reliable source of health coverage. Our past commitments resulted in our ability to develop, and provide access to, remarkable treatments that effectively suppress HIV and allow people to live healthier, more productive lives here at home and abroad. In recent years, we have been deeply concerned by our country's failure to prioritize support for domestic discretionary programs outside of defense and homeland security. The impact of our failure to invest in health care programs is already being felt and will be far-reaching and long lasting as our communities' public health infrastructures weaken and our capacity to lead the world in discovering new therapies for controlling deadly diseases such as HIV erodes.

The funding requests in our testimony largely represent the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV/AIDS organizations from across the country, and are estimated to be the amounts necessary to sustain and strengthen our investment in effectively combating HIV disease.

#### CDC'S NATIONAL CENTER FOR HIV, STD, TB PREVENTION (NCHSTP)

HIVMA strongly supports substantial increases in funding for the National Center for HIV/AIDS, STD and TB Prevention programs at the CDC. Programs supported by NCHSTP play a critical role in reducing the 40,000 new HIV infections that still occur annually in the United States. Sufficient resources must be devoted to supporting efforts to identify people with HIV earlier in the disease so that they can be effectively linked to the medical care and treatment that prevents or delays progression to AIDS. Tuberculosis is the major cause of AIDS-related mortality worldwide. It is critical that we shore up our ability as a Nation to address tuberculosis, especially drug-resistant tuberculosis here in the United States and in the developing world. With regard to these programs, we urge at least an increase of \$93 million for domestic HIV prevention programs and a funding level of \$252.4 million for CDC's Division of Tuberculosis Elimination.

In the absence of an HIV vaccine, preventing new HIV transmissions is our best weapon in reducing the number of people newly infected with HIV disease each year. We strongly support the CDC guidance recommending routine HIV testing for

adults in healthcare settings, but are gravely concerned about the absence of Federal resources to assist State health departments and healthcare institutions in implementing this guidance. According to the CDC, at least 25 percent of people with HIV infection in the United States do not know it and more than 39 percent of people with HIV infection progress to AIDS within 1 year of diagnosis. The expansion of HIV testing to identify individuals who are infected with HIV, but not yet aware of their status, is vital so that they can be optimally treated early in disease progression, and can reduce risky behaviors that put others at risk for HIV transmission.

An even more robust HIV prevention budget is necessary to conduct effective surveillance, and to target uninfected individuals who engage in high-risk behaviors if we are to dramatically reduce the 40,000 new HIV infections that occur each year in the United States. We also must continue to support science-based, comprehensive programs that target people who are not HIV positive but who are at high risk for HIV infection. We are seriously concerned that the resources committed to supporting a broad-based prevention agenda have diminished while funding for unproven and unscientific abstinence-only programs has increased. We strongly encourage Congress to halt this troubling trend. Adequate resources are needed to address the high prevalence rates among vulnerable populations, e.g., men and women of color and men who have sex with men. It is short sighted to compromise these programs in order to support newer initiatives.

Funding for HIV prevention activities at the CDC should be increased by at least the \$93 million recommended in the President's 2008 budget. These resources should be utilized to restore the \$26 million cut in HIV prevention cooperative agreements with State and local health departments, to enhance core surveillance cooperative agreements with health departments and to expand HIV testing in critical health care venues by funding testing infrastructure, the purchase of approved testing devices, including rapid tests and confirmatory testing.

Funding for tuberculosis prevention and control must increase substantially in order to address the emerging new threat of XDR-TB. HIVMA supports the recommendation of the Advisory Council for the Elimination of Tuberculosis (ACET) for a funding level of \$252.4 million for CDC's Division of Tuberculosis Elimination.

#### HIV/AIDS BUREAU OF THE HEALTH RESOURCES AND SERVICES ADMINISTRATION

HIVMA supports a total commitment of \$2.79 billion, an increase of \$682 million for the Ryan White CARE Act program. This recommendation includes a \$233 million increase for the AIDS Drug Assistance Program (ADAP) and at least an increase of \$35 million for Title III (Part C).

The Health Resources and Services Administration (HRSA) oversees programs that are vital to our communities' health care safety nets—and to the ability of our clinician members to provide state-of-the-art treatment and care to patients living with HIV/AIDS. Through grants to States, cities and community clinics, CARE Act funding helps us to meet the serious and complex needs of people with HIV/AIDS who are un- or under-insured by supporting the delivery of primary medical care, prescription drugs, diagnostic tests, mental health services, substance abuse treatment, and dental services in our communities.

We strongly support a substantial increase in CARE Act funding and would propose that the majority of new funding be targeted to HIV medical care under Title III (Part C) and to the AIDS Drug Assistance Program (ADAP) to ensure that uninsured and underinsured individuals with HIV/AIDS have access to a base line of lifesaving medical care and prescription drugs regardless of where they live. Funding increases are urgently needed for Title III programs. After years of flat funding or decreases in grant awards, we estimate that these programs require an increase of \$83.3 million in Federal funds. At a minimum, we urge you to include a \$35 million increase for Title III, Part C programs, with this additional funding targeted to current Title III grantees with the highest demonstrated increases in patient caseloads.

Many HIV clinical programs depend on funding from multiple parts of the CARE Act to create the comprehensive services that our patients need. We strongly encourage you to support funding increases of \$65 million for Title I, and \$57 million for the Title II base. Resources for domestic HIV care and treatment have eroded dramatically and this trend must be reversed or AIDS mortality in the United States could increase dramatically.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

HIVMA strongly supports at least a 6.7 percent increase for all research programs at the National Institutes of Health (NIH) including a 6.7 percent for the NIH Office

of AIDS research for fiscal year 2007. This level of increase, if sustained over several years, would halt the erosion in the Nation's medical research effort, and accelerate the pace of research that could improve the health and quality of life for millions of Americans.

The failure in recent years to adequately invest in biomedical research is taking its toll in deep cuts to clinical trials networks and significant reductions in the numbers of high quality, investigator-initiated grants that are approved. In the arena of AIDS research, virtual flat funding leads to reductions in critical research efforts to develop new therapeutics, to support the development of effective prevention technologies, and to finance vaccine development. A robust and comprehensive portfolio has been largely responsible for the dramatic gains that have been made in our knowledge about and response to the HIV virus, gains that have resulted in reductions in mortality from AIDS in the United States and other developing countries of nearly 80 percent. A continuing robust AIDS research effort is essential if we are to continue to make progress in preventing new infections, offering potent treatments with minimal toxicity, and developing a vaccine that may ultimately end the deadliest pandemic in human history. Our failure to make an adequate investment in this lifesaving research will compromise our ability to compare and evaluate optimum treatment and prevention strategies in resource-poor countries, and limit our ability to understand the appropriate role of new classes of antiretrovirals that are currently in development here at home for treatment and prevention.

The sheer magnitude of the number of people still living with HIV/AIDS in the United States and around the world—1,039,000 to 1,185,000 in the United States; 40 million globally—demands an increased investment in AIDS research if we are going to truly eradicate this devastating disease.

We also strongly support the NIH's Fogarty International Center (FIC), and believe that its programs and funding should be expanded. The FIC training programs play a critical role in developing self-sustaining health care infrastructures in resource-limited countries. By training local physicians in these countries, they are able to develop effective research programs that best address the health care, cultural and resource needs of residents in their respective countries.

Our Nation has made significant strides in responding to the HIV/AIDS pandemic here at home and around the world, but we have lost ground in recent years, particularly domestically, as funding priorities have shifted away from public health and research programs. This retreat on our past investments in AIDS research through NIH, surveillance and prevention programs through the CDC, and care and treatment through the Ryan White CARE Act program place the remarkable advancements of the past two decades in serious jeopardy. We have an opportunity to reverse this trend and to move forward with a budget that prioritizes funding for scientific discovery, public health, and care and treatment for those without resources or adequate insurance. With the support of this Congress, we have the opportunity to further limit the toll of this deadly infectious disease on our planet and to save the lives of millions who are infected or at risk of infection here in the United States and around the world.

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#### PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

The Infectious Diseases Society of America (IDSA) appreciates the opportunity to provide this statement to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies concerning fiscal year 2008 Federal funding for the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH). IDSA's statement speaks to the value of U.S. public health and infectious diseases research programs to the health of people in the United States and globally as well as the need to provide sufficient funding in fiscal year 2008 to sustain and improve these programs. While IDSA's leadership recognizes that current fiscal budgets are constrained due to the war in Iraq and the Federal budget deficit, we urge the subcommittee to support appropriate investments to protect all of us against the scourges wrought by infectious pathogens.

IDSA represents 8,400 infectious diseases physicians and scientists devoted to patient care, education, research, prevention, and public health. Our members care for patients of all ages with serious infections, including antibiotic-resistant bacterial infections, meningitis, pneumonia, tuberculosis, and those with cancer or transplants who have life-threatening infections caused by unusual microorganisms, food poisoning, and HIV/AIDS, as well as emerging infections like severe acute respiratory syndrome (SARS). Housed within IDSA is the HIV Medicine Association (HIVMA), which represents more than 3,600 physicians working on the frontline of the HIV/AIDS pandemic. HIVMA members conduct research, implement prevention

programs, and provide clinical services to individuals who are infected with HIV/AIDS. IDSA and HIVMA are the principal organizations representing infectious diseases and HIV physicians in the United States.

Over the past several decades, the United States has made many significant advances in the fight against infectious diseases. For example, CDC's public health prevention and control strategies have reduced infectious diseases morbidity and mortality rates in the United States and globally. NIH-funded research and training has led to critical new discoveries while at the same time supporting economic growth in incubator sites across the country, fostering innovation and competition, and making the United States the leader in global biomedical research. Needless to say, much work remains to be done as infectious diseases remain the second leading cause of death worldwide and the third leading cause of death in the United States. Of greatest concern:

- Avian flu is an imminent threat to the United States. Despite the increased attention and progress that has been made in preparing for an influenza pandemic, the Institute of Medicine and virtually all experts conclude that the United States is woefully unprepared to sufficiently respond to pandemic flu and many gaps and challenges remain.
- Antimicrobial resistant infections have created a “silent epidemic” in communities and hospitals across the country—methicillin-resistant *Staphylococcus aureus* (MRSA), for example, is crippling and killing a growing number of previously healthy people including children, athletes, and military recruits as well as many elderly people; and
- On a global scale, infectious diseases annually cause 15 million deaths—HIV/AIDS, tuberculosis, and malaria alone account for one third of these deaths.

#### PANDEMIC AND SEASONAL INFLUENZA FISCAL YEAR 2008 FUNDING RECOMMENDATION

IDSA is deeply appreciative to the committee members for your support of increased funding for pandemic and seasonal influenza preparedness efforts as well as for the inclusion of additional pandemic influenza funding in the pending emergency supplemental appropriations bill. IDSA also applauds Congress and the administration for enacting this past December the Pandemic and All-Hazards Preparedness Act and establishing the Biomedical Advanced Research Development Authority (BARDA) within the Department of Health and Human Services. We request that Congress ensure significantly increased and sustained long-term funding to support critical activities authorized by the act. We are deeply concerned that the Federal, State, and local preparedness and response goals outlined in the act cannot be achieved without significantly increased, long-term, sustainable funding.

In addition, experts and Federal Government officials agree that the development of a pandemic vaccine is the strategy most critically needed to protect U.S. citizens from a pandemic. IDSA has proposed the establishment of a multinational Pandemic Influenza Vaccine Master Program led by the United States to outline a comprehensive approach that will systematize, coordinate, and strengthen vaccine research and development (R&D), increase production capacity, accelerate licensure, guarantee equitable global distribution, and monitor vaccine performance and safety. IDSA has proposed that a U.S. commitment of \$2.8 billion is needed in fiscal year 2008 to initiate the master program and to serve as a catalyst for additional financial support from international partners. Included within our fiscal year 2008 master program proposal is a \$750 million commitment for the new BARDA program. BARDA will enhance and accelerate the R&D activities necessary to produce new medical countermeasures that will protect U.S. citizens from pandemic influenza.

#### OTHER FISCAL YEAR 2008 FUNDING RECOMMENDATIONS

##### *Centers for Disease Control and Prevention*

IDSA recommends a total budget level of \$8.7 billion for CDC's discretionary programs in fiscal year 2008 including an increase of at least \$686.4 million for CDC's Infectious Diseases Program.

As part of our proposed increase in CDC's total ID Program funding, IDSA supports:

*An increase of at least \$50 million for CDC's Antimicrobial Resistance Program*

Antimicrobial resistance is a priority funding area for IDSA in fiscal year 2008. Microbes' ability to become resistant to antimicrobial drugs not only impacts individual patients, but also can have a devastating impact on the general population as resistant microbes pass from one individual to another. A multi-pronged approach is essential to limit the impact of antibiotic resistance on patients and public

health. Our proposed increase in antimicrobial resistance funding will enable CDC to strengthen programs such as the National Healthcare Safety Network (NHSN), which generates national prevalence data to track the spread of multi-drug-resistant organisms in health care settings; expand its surveillance of clinical and prescribing data that are associated with drug-resistant infections; gather morbidity and mortality data due to resistance; educate physicians and parents about the need to protect the long-term effectiveness of antibiotics; and strengthen infection control activities across the United States. Broadening the number of CDC's extramural grants in applied research at academic-based centers also would harness the brainpower of our Nation's researchers.

*An increase of at least \$281 million for CDC's Immunization Program*

Vaccines are one of the greatest public health successes ever achieved, helping to reduce, and in some cases eliminate, the spread of infectious diseases in the United States and abroad. In the United States, immunization of a birth cohort, or a year's worth of children born, saves 33,000 lives and \$42 billion in costs. Important new vaccines have been licensed for rotavirus, pertussis, zoster, and human papillomavirus (HPV). The HPV vaccine could prevent the majority of cases of cervical cancer. Yet these new vaccines add new costs. Without additional funding of CDC's 317 Program, these vaccines will not be available to under-insured children and the infrastructure to administer vaccines and track their safety will be compromised. IDSA also is very concerned that adult immunization rates are much too low. Vaccines can be cost-saving, but new efforts are needed to make sure that access is available for all age groups. We cannot afford, however, to take scarce funds from childhood immunization to fund adult immunization—a significant new investment is required.

For these reasons, we support a total fiscal year 2008 appropriation level of \$802.4 million for CDC's discretionary immunization program. This amount includes \$387 million for the purchase of childhood vaccines, and \$200 million for childhood immunization operations/infrastructure grants to States. In parallel fashion, as a first step toward meeting extensive needs in the adult arena, it includes \$88 million for purchase of adult vaccines and \$45 million for adult operations and infrastructure grants to States. Finally this amount includes \$82.4 million for prevention, safety, and administrative activities.

*An increase of at least \$93 million for CDC's HIV Prevention Program*

These additional resources should be utilized to restore cuts in HIV prevention cooperative agreements with State and local health departments, to enhance core surveillance cooperative agreements with health departments, and to expand HIV testing in critical health care venues by funding testing infrastructure and the purchase of approved testing devices, including rapid tests and confirmatory testing.

*An increase of at least \$252.4 million for CDC's TB Elimination Program*

Recent cuts of 14 percent have eroded national tuberculosis (TB) control at a time of increased threat posed by extensively-drug resistant TB and multi-drug resistant TB. Additionally, a total of \$350 million is needed across CDC as well as at the NIH to support research on TB vaccines, diagnostics, drugs, and related clinical research.

—An increase of \$10 million for CDC's Public Health and Human Services Block Grant

We are concerned that the President's proposed budget once again proposes to eliminate CDC's Public Health and Human Services Block Grants, which provide States the flexibility to respond to infectious diseases outbreaks, among other events. IDSA opposes the termination of this program and instead supports a healthy increase of \$10 million.

NATIONAL INSTITUTES OF HEALTH

IDSA recommends that Congress support at least a 6.7 percent increase for NIH research programs and particularly for the National Institute of Allergy and Infectious Diseases' (NIAID) AIDS research; non-AIDS, non-bioterrorism infectious diseases research, particularly antimicrobial resistance, antimicrobial therapy, and pandemic influenza research; and biodefense research. IDSA also supports a doubling of the Fogarty International Center's (FIC) budget to \$134 million in fiscal year 2007.

Advancing biomedical research and maintaining the U.S. leadership in this arena requires a consistent, long-term strategy and continued strong investments. We must not be short-sighted in our approach. In light of the rise in emerging and re-emerging diseases, and particularly, the trend of previously treatable organisms evading our best drugs, IDSA urges more aggressive, sustained scientific effort and

funding dedicated not only to understanding the fundamental mechanisms of these diseases, but also support for clinical studies and translational research as a stepping stone to the development of new therapies. In addition, little research has been devoted to defining optimal antimicrobial dosing regimens, particularly related to the minimal duration of therapy necessary to cure many types of infections. Such studies require a long-term commitment and are not likely to be funded by pharmaceutical manufacturers. The consensus of many experts is that infections are frequently treated for longer periods of time than are necessary, needlessly increasing antimicrobial resistance. For this reason, IDSA urges the establishment of a Clinical Trials Network at NIH, similar to the AIDS Clinical Trials Group, devoted to defining optimal antibacterial therapy. Well-designed, multi-center randomized controlled trials that define the necessary length of therapy would create an excellent basis of evidence from which coherent and defensible recommendations could be developed.

IDSA also is concerned that NIH research project grant funding has steadily declined after peaking in 2004—the average award would be 8.4 percent smaller in 2008 than in 2004. IDSA fears that we are discouraging and potentially sacrificing an entire generation of young scientists if they conclude that NIH grants are unattainable. Sustainable and predictable funding is needed in this area. Finally, IDSA supports a doubling of FIC's budget. FIC oversees vital programs which train health professionals in resource-limited countries about how best to attack AIDS, tuberculosis, malaria, and other infectious diseases.

#### CONCLUSION

Today's investment in infectious disease research, prevention, and treatments will pay significant dividends in the future by dramatically reducing health care costs and improving the quality of life for millions of Americans. In addition, U.S. leadership in infectious diseases research and prevention will translate into worldwide health benefits. We urge the subcommittee to continue to demonstrate leadership and foresight in this area by appropriating the much-needed resources outlined above in recognition of the lives and dollars that ultimately will be saved.

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#### PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

##### SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

Provide a 6.7 percent increase for fiscal year 2008 to the National Institutes of Health (NIH) budget. Within NIH, provide proportional increases of 6.7 percent to the various institutes and centers, specifically, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Office of Research on Women's Health (ORWH).

Accelerate funding for extramural clinical and basic functional gastrointestinal disorders (FGID) and motility disorders research at NIDDK.

Continue to urge NIDDK to develop a strategic plan on irritable bowel syndrome (IBS) with the purpose of setting research goals, determining improved treatment options for IBS sufferers, and assisting in recruitment of new investigators to conduct IBS research.

Urge the National Institute of Child Health and Human Development (NICHD) and NIDDK to continue to support research into fecal and urinary incontinence, including the development of a standardization of scales to measure incontinence severity and quality of life and to develop strategies for primary prevention of fecal incontinence associated with childbirth.

Provide funding to NIDDK and the National Cancer Institute (NCI) for increased research on the causes of esophageal cancer.

Thank you for the opportunity to present this written statement regarding the importance of functional gastrointestinal and motility disorders research. IFFGD has been serving the digestive disease community for 15 years. We work to broaden the understanding of functional gastrointestinal and motility disorders in adults and children. IFFGD raises awareness on disorders and diseases that many people are uncomfortable and embarrassed to discuss. The prevalence of fecal incontinence and irritable bowel syndrome or IBS, as well as a host of other gastrointestinal disorders affecting both adults and children, is underestimated in the United States. These conditions continue to remain hidden in our society. Not only are they misunderstood, but the burden of illness and human toll has not been fully recognized.

Since its establishment, IFFGD has been dedicated to increasing awareness of functional gastrointestinal and motility disorders, among the public, health profes-

sionals, and researchers. While maintaining a high level of public education efforts, IFFGD has also become recognized for our professional symposia. We consistently bring together a unique group of international multidisciplinary investigators to communicate new knowledge in the field of gastroenterology. Next month IFFGD will be hosting our Seventh International Symposium on Functional Gastrointestinal Disorders, bringing scientists, researchers, and clinicians from across the world together to discuss the current science and opportunities on IBS and other functional gastrointestinal and motility disorders. Also, in November 2002, we hosted a conference on fecal and urinary incontinence, the proceedings of which were published in *Gastroenterology*, the official journal of the American Gastroenterological Association (AGA). The IFFGD has also been working with the National Institute of Child Health and Human Development (NICHD), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the Office of Medical Applications of Research (OMAR) in the NIH Office of the Director on the NIH State of the Science Conference on Fecal and Urinary Incontinence to be held in December 2007.

The majority of the diseases and disorders we address have no cure. We have yet to completely understand the pathophysiology of the underlying conditions. Patients face a life of learning to manage a chronic illness that is accompanied by pain and an unrelenting myriad of gastrointestinal symptoms. The costs associated with these diseases are enormous; estimates range from \$25–\$30 billion annually. The human toll is not only on the individual but also on the family. Economic costs spill over into the workplace. In essence, these diseases reflect lost potential for the individual and society. The IFFGD is a resource that provides hope for hundreds of thousands of people as they try to regain as normal a life as possible.

#### IRRITABLE BOWEL SYNDROME (IBS)

IBS strikes people from all walks of life. It affects 25 to 45 million Americans and results in significant human suffering and disability. This chronic disease is characterized by a group of symptoms, which include abdominal pain or discomfort associated with a change in bowel pattern, such as loose or more frequent bowel movements, diarrhea, and/or constipation. Although the cause of IBS is unknown, we do know that this disease needs a multidisciplinary approach in research and often treatment.

IBS can be emotionally and physically debilitating. Due to persistent bowel unpredictability, individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home.

In the House and Senate fiscal years 2004, 2005, 2006, and 2007 Labor, Health and Human Services, and Education Appropriations bills, Congress recommended that NIDDK develop an IBS strategic plan. The development of a strategic plan on IBS would greatly increase the institute's progress toward the needed research on this functional gastrointestinal disorder, as well as serve to advance our understanding of this disease, determine improved treatment options for IBS sufferers, and assist in recruiting new investigators to conduct IBS research. NIDDK is formulating an action plan for digestive diseases through the National Commission on Digestive Diseases and has indicated that IBS will be included as a component of this overall plan. IBS must be given sufficient attention, however, in order to increase the functional gastrointestinal disorders (FGID) and motility disorders research portfolio at NIDDK.

#### FECAL INCONTINENCE

At least 6.5 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and in the elderly of both sexes. Often it is a symptom associated with various neurological diseases and many cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, uterine cancer, and a host of other diseases.

Damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction can cause fecal incontinence. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most attempt to hide the problem for as long as possible. They withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly burdens families and is the primary

reason for nursing home admissions, an already huge social and economic burden in our increasingly aged population.

In November 2002, the IFFGD sponsored a consensus conference—"Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities." Among other outcomes, the conference resulted in six key research recommendations:

- More comprehensive identification of quality of life issues associated with fecal incontinence and improved assessment and communication of treatment outcomes related to quality of life.
- Standardization of scales to measure incontinence severity and quality of life.
- Assessment of the utility of diagnostic tests for affecting management strategies and treatment outcomes.
- Development of new drug compounds offering new treatment approaches to fecal incontinence.
- Development and testing of strategies for primary prevention of fecal incontinence associated with childbirth.
- Further understanding of the process of stigmatization as it applies to the experience of individuals with fecal incontinence.

The IFFGD has been working with the NICHD, NIDDK, and OMAR on a NIH State of the Science Conference on Fecal and Urinary Incontinence that is scheduled to take place in December 2007. The goal of this conference will be to assess the state of the science and outline future priorities for research on both fecal and urinary incontinence; including, the prevalence and incidence of fecal and urinary incontinence, risk factors and potential prevention, pathophysiology, economic and quality of life impact, current tools available to measure symptom severity and burden, and the effectiveness of both short- and long-term treatment. Once the conference is completed, NIH must prioritize implementation of the recommendations of this important conference.

#### GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Gastroesophageal reflux disease, or GERD, is a common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. But sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. One uncommon complication is Barrett's esophagus, a potentially pre-cancerous condition associated with esophageal cancer. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. There are several treatment options available for individuals suffering from GERD.

Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year. GER results from an immature upper gastrointestinal motor development. The prevalence of GER is increased in premature infants. Many infants require medical therapy in order for their symptoms to be controlled. Up to 25 percent of older children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction. In this population, the natural history of GER is similar to that of adult patients, in whom GER tends to be persistent and may require long-term treatment.

#### GASTROPARESIS

Gastroparesis, or paralysis of the stomach, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, including being present in 30 percent to 50 percent of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications, especially narcotic pain medications. In many patients the cause of the gastroparesis cannot be found and the disorder is termed idiopathic gastroparesis. Over the last several years, as more is being found out about gastroparesis, it has become clear this condition affects many people and the condition can cause a wide range of symptoms of differing severity.

FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS AND THE NATIONAL  
INSTITUTES OF HEALTH

The International Foundation for Functional Gastrointestinal Disorders recommends an increase of 6.7 percent to the budget of NIH, and a 6.7 percent increase for NIDDK and NICHD. However, we request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We urge the subcommittee to provide the necessary funding for the expansion of the NIDDK's research program on FGID and motility disorders. This increased funding will allow for the growth of new research on FGID and motility disorders at NIDDK, a strategic plan on IBS, and increased public and professional awareness of FGID and motility disorders. In addition, we urge the subcommittee to continue to support and provide adequate funding to the Office of Research on Women's Health (ORWH) under the NIH Office of the Director, particularly for their Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCORs) program and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program. The ORWH supports important research into IBS.

A primary tenant of IFFGD's mission is to ensure that clinical advancements concerning GI disorders result in improvements in the quality of life for those affected. By working together, this goal will be realized and the suffering and pain millions of people face daily will end. Thank you.

PREPARED STATEMENT OF THE JEFFREY MODELL FOUNDATION

Mr. Chairman and members of the subcommittee: Thank you for the opportunity to testify before you today. I am Vicki Modell and, along with my husband Fred, we created the Jeffrey Modell Foundation in 1987 in memory of our son, who died at the age of 15 as a result of a life long battle against one of the estimated 140 primary immunodeficiency (PI) diseases.

Today I wish to discuss with you two important initiatives for the Congress, the CDC, and the Jeffrey Modell Foundation to collaborate on that will achieve the following:

- Continue to educate and raise awareness about primary immunodeficiency diseases among physicians, other health care providers, and the public through a highly successful program that has, to date, generated \$10 private for every \$1 public invested; and
- Launch a pilot program that will extend newborn screening to Severe Combined Immune Deficiency, the most lethal of all PI diseases, saving lives and saving money.

The Jeffrey Modell Foundation is an international organization located in New York City. In its 21 years of existence, the Foundation has grown into the premier advocacy and service organization on behalf of people afflicted with primary immunodeficiency diseases. As a demonstration of the extent to which the JMF leads in the field, please consider the following:

- The Foundation has established Jeffrey Modell Research and Diagnostic Centers at 34 academic and teaching hospitals in the United States and abroad.
- The Foundation conducts a national physician education and public awareness campaign, currently funded with approximately \$2.5 million appropriated by this committee to the Centers for Disease Control and Prevention (CDC) and awarded to the JMF. To date, the Foundation has leveraged the Federal money to generate in excess of \$75 million in donated media and corporate contributions with almost 250,000 placements/airings on television, radio, print, and other public media, as well as a 30-minute program produced for PBS. CME physician symposia have been held at leading academic teaching hospitals throughout the Nation. It has also included mailings to physicians in a variety of specialist and generalist fields, including pediatrics and several pediatric specialties, family practice, and internal medicine, as well as to school nurses, clinical and registered nurses and daycare centers throughout the United States.
- In addition, the Foundation has long been a provider of direct patient services such as KIDS Days that give young people a chance to meet and share experiences with others similarly situated in their communities in a fun atmosphere that encourages a feeling of normalcy in patients.

First and foremost, Mr. Chairman, I am here today to thank you and all the members of this committee. Over the last 10 years that we have been coming to Washington, we have been given the opportunity to build a partnership with the Congress, the Centers for Disease Control and Prevention, the National Institutes of Health, the Health Resources and Services Administration, as well as with our own supporters in the private sector, including the pharmaceutical and biotechnology in-

dustries, and other concerned donors. We believe that we have maximized the benefits for patients from the support that this subcommittee has afforded the Foundation.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

This subcommittee is currently funding CDC with \$2.5 million for physician education and public awareness of primary immune deficiencies. The Jeffrey Modell Foundation operates the program under a contract with CDC. Since the campaign's inception, it has generated more than \$75 million in donated media, including television and radio spots, magazine ads, billboards, airport signs and other print media, as well as other corporate support. Every \$1 provided by the committee has been leveraged into more than \$10 of private money for this education and awareness program.

In a national survey conducted on behalf of the Foundation, funded by a grant from the CDC, one in three Americans state that they have heard of Primary Immunodeficiency. When 502 pediatricians and family practice physicians were asked about PI, 85 percent of physicians consider PI to be rare or extremely rare (1 in 5,000–10,000 patients). However, the National Institutes of Health cites the prevalence of 1 in 500. This disparity shows how much education the medical community still needs.

The progress being made by the campaign is significant. As reported by the Foundation's Centers for Primary Immunodeficiencies, there has been a 79 percent increase in the number of diagnosed patients, a 58 percent increase in the number of patients receiving treatment, and a 57 percent increase in patients referred to JMF specialized centers. These increases are reflected on an annual basis for each year of the campaign. The most meaningful statistic is that there has been an annual 256 percent increase in the number of diagnostic tests performed, showing that the campaign is raising patients' and physicians' awareness of PI. The campaign has generated over 6 million hits to the JMF website annually, 500,000 unique visits to the JMF website annually and over 12,000 calls to the JMF hotline, further evidence of the campaign's effectiveness.

Two years ago the subcommittee increased the CDC funding for the campaign by approximately \$500,000 in order to expand the campaign to target the underserved minority population. Research shows that the incidence of PI does not vary between races or among ethnic groups. To reach its intended audience, the minority campaign must run ads on different radio stations and television networks and have space in different print media. Since the program's launch, the campaign has leveraged the \$1 million in Federal funds to generate over \$17 million in donated media and has had almost 60,000 airings/placements.

We respectfully request that this subcommittee continue to fund this program at \$2.5 million in fiscal year 2008 (the level requested in the President's budget), allowing the Foundation to continue both the original education and awareness program and the targeted minority campaign.

#### QUALITY OF LIFE AND ECONOMIC IMPACT STUDY

In 2006, the Foundation set out to examine the impact of early diagnosis in a rigorous manner. Physician experts at the 118 Jeffrey Modell Diagnostic and Referral Centers were contacted. Each of the Centers was asked to examine patient records 1 year prior to diagnosis and for the year following diagnosis and treatment. The data, which included 532 patient records, was collected by the Foundation and reviewed by members of the Foundation's Medical Advisory Board.

The results of the study clearly demonstrate that the quality of life of undiagnosed patients is significantly lower than that of diagnosed patients. Undiagnosed patients suffer from chronic infections an average of 44.7 days per year compared to 12.6 days for diagnosed patients. On average, undiagnosed patients are treated with antibiotics 166.2 days per year compared to 72.9 days per year. Undiagnosed patients spend 14.1 more days of the year in hospitals than diagnosed patients. Also, the study found that undiagnosed patients missed 33.9 days of work or school compared to only 8.9 days missed by diagnosed patients.

Besides being sicker, requiring more care, and more time out of the workforce, ultimately, an undiagnosed patient costs the healthcare system \$102,552 per year compared to \$22,610; diagnosing a patient with PI saves \$79,942 per year. According to NIH, there are as many as 500,000 undiagnosed patients in this country; these undiagnosed patients cost the healthcare system approximately \$40 billion annually. These costs underscore the importance of early identification and treatment for PI patients.

## NEWBORN SCREENING PROGRAM

Mr. Chairman, our dedication to the importance of early diagnosis has led us to field of newborn screening. And here we have an opportunity for the action of this subcommittee to save lives, literally. Severe combined immune deficiency (SCID) is the most severe form of PI and is fatal, if an infant is not diagnosed and treated within the first year of life. Within the first few months of life, the infant will suffer from one or more serious infections, including pneumonia, meningitis or blood-stream infections.

Newborn screening is the solution to this life-threatening condition. Last fall the Foundation sponsored a meeting in conjunction with the CDC Foundation to examine the state of the science regarding newborn screening for SCID. We learned at that meeting that doctors can diagnose SCID with 99 percent accuracy; and we learned that they can treat it with a 95 percent success rate using bone marrow transplantation to restore the immune system before the infant develops any serious infections. If a diagnosis of SCID is made within the infant's first 2 months of life, treating SCID costs under \$10,000. However, by the 9th or 10th month of life, if the infant survives that long, the costs of transplantation and other medical complications are over \$1 million and the success rate falls dramatically.

Based on discussions at last fall's meeting at the CDC, both Wisconsin and New York are prepared to begin a pilot program to screen newborns for SCID. In Wisconsin, a collaboration between the Children's Hospital of Wisconsin, the Medical College of Wisconsin and the Wisconsin State Laboratory of Hygiene has been established to begin the program by replicating the State's current screening model for cystic fibrosis. The Wisconsin State Laboratory of Hygiene currently runs 300-500 tests per day, 6 days a week, easily accommodating all the newborns in the State. Screening tests are conducted between the 3rd and 7th day of life, and a report is delivered by the lab to the pediatrician within 7 days. New York State health officials are going to monitor Wisconsin's program to determine how the screen needs to be altered to handle New York's 250,000 live births a year.

To start this pilot, both the Children's Hospital of Wisconsin and the Foundation each contributed to this effort. The Foundation has estimated that it will cost approximately \$560,000 per State to begin screening for SCID. Once the pilot program demonstrates efficacy, SCID screening will cost a maximum of between \$6.50 and \$7 per child.

To support the efforts of Wisconsin and New York, we respectfully request that this subcommittee increase funding for CDC's Environmental Health Laboratory program by \$750,000, specifically to fund the pilot program to screen newborns for SCID in Wisconsin and New York. We anticipate that this will be a one-time cost. Once the pilot is evaluated and methods are proven, States will be able to add this test to their screening panel.

## CONCLUSION

With the support the Jeffrey Modell Foundation has received from this subcommittee, we have been able to increase significantly the public's awareness of PI and most importantly, thanks to your support, we have been able to save lives. The Federal Government's investment in this campaign is producing results far beyond anything that even we had anticipated. Many more children are being tested and treated; lives are being saved.

We understand that the subcommittee must make difficult decisions in this fiscal environment. However, the Foundation's education and awareness campaign has been recognized as a model collaborative program that has successfully leveraged Federal dollars in a manner rarely seen. We now know the financial burden an undiagnosed patient places on the healthcare system; there is no reason to spend \$40 billion annually on the treatment of undiagnosed patients. For every Federal dollar spent on the campaign and research, the potential to save lives increases exponentially. This is precisely the kind of public-private partnership that should be encouraged. It works. It saves lives. And, it is the best example of bringing scientific advances to every citizen regardless of their station in life.

After 5 years of funding for the campaign, we believe it is time for this subcommittee to take the next step with us and financially support newborn screening for SCID. The science shows the screening is accurate and the treatment is successful and cost effective. Diagnosing, transplanting and curing just one baby will make the all of our efforts worthwhile; but, there is no reason to stop at one. We will continue to advocate for the expansion of this pilot program and eventually the inclusion of the screen for SCID on every State's list of required newborn screening.

Thank you, Mr. Chairman, for the opportunity to present this testimony to the subcommittee.

## PREPARED STATEMENT OF THE LUPUS FOUNDATION OF AMERICA

## SUMMARY

The Lupus Foundation of America (LFA) is the Nation's leading non-profit voluntary health organization dedicated to improving the diagnosis and treatment of lupus, supporting individuals and families affected by the disease, increasing awareness of lupus among health professionals and the public, and finding the causes and cure. LFA respectfully calls upon Congress to provide the following allocations in the fiscal year 2008 Labor-Health and Human Services-Education (LHHS) appropriations measure to reduce and prevent suffering from lupus:

- \$3.25 million for the National Lupus Patient Registry (NLPR) at the National Center for Chronic Disease Prevention and Health Promotion within the Centers for Disease Control and Prevention (CDC) to sustain current epidemiological efforts and expand the registry to seven sites. Such an expansion would ensure that the registry includes all forms of lupus and all affected populations, particularly African Americans, Hispanics, and Asian Americans, who are disproportionately at-risk for—and have worse outcomes associated with—lupus.
- \$30.8 billion (a 6.7 percent increase) for the National Institutes of Health (NIH) to support lupus research. Specifically, we urge the subcommittee to provide a 6.7 percent increase to each of the following institutes and centers, which play an integral role in lupus research: NCMHD, NHGRI, NHLBI, NIAID, NIAMS, NIDDK, NIEHS, and NINDS. Moreover, we respectfully call on Congress to move to provide a 33 percent increase for lupus research for each of the next three fiscal years.
- \$1 million in new funding for the HHS Office on Women's Health to support a sustained national lupus education and awareness campaign. These educational efforts would be directed toward healthcare professionals who diagnose and treat people with lupus, with an emphasis on reaching those individuals at highest risk—women of color—a health disparity that remains unexplained.

## BACKGROUND ON LUPUS

As you may know, lupus—a debilitating, chronic autoimmune disease that causes inflammation and tissue damage to virtually any organ system—affects as many as 2 million Americans. Since lupus is a systemic disease, it can cause significant disability and even death. Lupus can be particularly difficult to diagnose because its symptoms are similar to those of many other diseases, and major gaps exist in understanding the causes and consequences of the disease. Lupus affects women nine times more often than men and disproportionately impacts women of color. Our scientific advisors note that lupus is the prototypical autoimmune disease and indicate that finding answers to questions about lupus also may provide understanding about other autoimmune diseases affecting 22 million Americans. Tragically, there have been no new drugs approved by the Food and Drug Administration specifically for lupus in nearly 40 years. Currently, there is no cure for lupus; available treatments can lead to damaging side effects and can adversely impact quality of life. LFA maintains that the Nation must significantly increase its attention to—and investment in—lupus research, education, and awareness to help ensure that much-needed progress is made in lupus diagnosis and treatment—eventually achieving a cure.

## CDC NATIONAL LUPUS PATIENT REGISTRY

LFA respectfully requests that the subcommittee provide \$3.25 million in fiscal year 2008 to the CDC National Lupus Patient Registry (NLPR). The NLPR plays an integral role in lupus epidemiological studies which provide important insight into the disease. The establishment of the NLPR was the first nationwide step in the CDC's effort to assess the prevalence and incidence of lupus. The NLPR serves as a conduit for the collection of valid and reliable data for epidemiological studies to better understand and measure the burden of illness, assess the social and economic impact of the disease, and stimulate additional private investment by industry in the development of new, safe, and effective therapies—and hopefully a cure—for lupus.

Currently, the NLPR involves two study sites—in Georgia and Michigan. The information collected through the Emory University School of Medicine and the Michigan Department of Community Health (in collaboration with the University of Michigan) stems from a multi-pronged approach using data from laboratory tests, interviews with physicians who treat lupus patients, hospital data, and other sources. While the data gleaned from the current sites are important and useful, unfortunately—due to limited resources—the NLPR does not include information on

all forms of lupus and all populations affected by the disease. This constrained scope, depth, and breadth of the NLPR limits its utility to researchers and does not allow for adequate exploration of the health disparities apparent among those diagnosed with lupus.

Existing epidemiological data on lupus are decades old and no longer reliable. Population-based epidemiological studies of lupus must be conducted at strategically-located sites throughout the Nation that will provide accurate data on all forms of lupus (i.e. systemic lupus, primary discoid lupus, drug-induced lupus, neonatal lupus, antiphospholipid antibodies) and the disparity among the various racial and ethnic populations. The LFA and its scientific and medical advisors recommend that the NLPR be expanded to an additional five sites, which should represent the populations that are disproportionately affected by lupus—principally African Americans, Hispanics, Asian Americans, and Native Americans. To that end, LFA urges the subcommittee to provide \$3.25 million in fiscal year 2008 and to include language in the report accompanying the fiscal year 2008 LHHHS measure that encourages the CDC to create a common data entry and management system across all study sites, to collaborate with a consortium of academic health centers with an expertise in lupus epidemiology, and ensure adequate numbers and locations of study sites and sufficient numbers of individuals of all racial and ethnic backgrounds.

#### RESEARCH FOR BETTER TREATMENTS AND A CURE

The LFA has long been concerned about the inadequate levels of Federal investment in lupus research. Unfortunately, during the doubling of NIH funding, lupus did not receive its proportional increase; now that NIH funding has flattened, lupus research is in danger of falling even further behind. However, after a tragic 40 year dearth of specific new treatments to manage this debilitating and devastating disease, lupus researchers are on the brink of major discoveries that could substantially advance lupus research, leading to better treatments, and possibly a cure.

To achieve these much-needed breakthroughs, LFA maintains that Federal research funding must be increased significantly. It is important to note that level or decreased NIH funding could bring to a standstill clinical trials and large observational studies, and could curtail research on those at highest risk for lupus, women of color. Furthermore, insufficient Federal funding also could slow much-needed genetic research, when we are just discovering the critical components that may contribute to lupus and its adverse effects. Therefore, it is critical that biomedical researchers be provided the necessary resources to continue seeking answers to the questions that will lead to safer and more effective lupus treatments. To that end, LFA has joined with the broader public health and research communities in supporting an overall 6.7 percent increase for the NIH in fiscal year 2008. LFA has identified a number of NIH institutes and centers whose research activities are critical to identifying improved treatments and a cure for lupus, and as noted above, we urge that each of these entities receive a 6.7 percent increase in fiscal year 2008: NCMHD, NHGRI, NHLBI, NIAID, NIAMS, NIDDK, NIEHS, NIDDK and NINDS. We urge Congress to move to provide a 33 percent increase for lupus research for each of the next 3 fiscal years.

**NIAMS.**—Lupus affects the skin, bones, joints, and connective tissue. NIAMS is integral to making gains in lupus treatment and identifying a cure. LFA asks that the subcommittee encourage NIAMS to significantly expand research related to lupus, with a particular focus on understanding the underlying mechanisms of disease, gene-gene and gene-environmental interactions, lupus and kidney disease, biomarkers, pediatric research, environmental factors, and factors related to health disparities and comorbidities associated with lupus.

**NIAID.**—Lupus is a dysfunction of the immune system which warrants greater examination. LFA's scientific and medical advisors maintain that NIAID has an integral and more significant role to play in lupus research. To that end, LFA respectfully requests that the subcommittee urge NIAID to take a leadership role in lupus research and expand and intensify genetic, clinical, and basic research related to lupus, with a particular focus on gene-gene and gene-environmental interactions, biomarkers, pediatric research, environmental factors, and factors related to health disparities and comorbidities associated with lupus.

**NCMHD.**—Nine out of 10 people with lupus are women; lupus is two to three times more common among women of color than Caucasian women. Lupus mortality has increased over the past 3 years and is higher among older African American women. We urge the subcommittee to encourage NCMHD to collaborate with extramural researchers and LFA to ensure that these terrible disparities receive the attention—and interventions—they deserve.

**NHGRI.**—Lupus likely is a polygenetic disease. As such, LFA asks the subcommittee to encourage NHGRI to undertake efforts to help identify the gene(s) associated with lupus.

**NHLBI.**—Lupus attacks the heart, lungs, blood, and blood vessels. LFA encourages the subcommittee to urge NHLBI to expand and intensify research on lupus, with a special emphasis on lupus and early onset of cardiovascular disease.

**NIEHS.**—Lupus disease activity can be triggered by certain environmental factors. LFA encourages the subcommittee to urge NIEHS to undertake additional lupus related research activities to help identify environmental factors, biomarkers, and gene-environmental interactions associated with the disease.

**NIDDK.**—Lupus causes lupus nephritis—inflammation of the kidneys. LFA asks the subcommittee to urge NIDDK to undertake studies into this condition, which is one of the most serious manifestations of lupus.

**NINDS.**—Lupus attacks the blood vessels in the brain, causing seizures, psychosis, and stroke. LFA urges the subcommittee to encourage NINDS to expand its research related to lupus.

#### INCREASED AWARENESS AND EDUCATION FOR BETTER OUTCOMES

Too many affected individuals and their health professionals remain unaware of the signs and symptoms of lupus, delaying correct diagnoses and often leading to poorer outcomes. Therefore, the LFA's medical advisors recommend a sustained national lupus education campaign to improve awareness and education of the public and health professionals to reduce and prevent suffering from lupus. LFA respectfully requests the subcommittee provide \$1 million in new fiscal year 2008 funding to the Office on Women's Health to support this important endeavor. LFA welcomes the opportunity to work with HHS staff and others to ensure the campaign's success.

#### SUMMARY

LFA very much appreciates the opportunity to submit written testimony on fiscal year 2008 funding for lupus research, epidemiological studies, education and awareness efforts. We understand that the Nation faces unprecedented fiscal challenges; however, LFA has serious concerns that without new Federal investments, we will not make the necessary progress in lupus-related biomedical research and epidemiology at such a promising time. LFA stands ready to work with the subcommittee and others in Congress to reduce and prevent suffering from lupus.

#### PREPARED STATEMENT OF THE LYMPHOMA RESEARCH FOUNDATION

I am Melanie Smith, director of Public Policy and Advocacy for the Lymphoma Research Foundation (LRF). On behalf of the lymphoma survivors, researchers, and caregivers who are represented by LRF, I would like to express our appreciation for the opportunity to submit a statement to the House Appropriations Subcommittee for Labor, Health and Human Services, and Education. We will focus our remarks on the opportunities and challenges in lymphoma research and the potential for extending and improving the lives of those who are diagnosed with lymphoma.

LRF is the Nation's largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and healthcare professionals with critical information on this disease. LRF's mission is to eradicate lymphoma and serve those touched by this disease. To that end, we have developed a research program through which we fund leading lymphoma researchers at outstanding academic institutions. LRF-funded research focuses on understanding the basic mechanisms of lymphoma as well as enhancing the available treatments for the disease. To date, LRF has funded more than \$34.7 million in lymphoma research.

LRF is especially proud of its 3-year initiative to provide more than \$21 million for a special mantle cell lymphoma program comprised of eighteen clinical and/or laboratory-based projects in North America and Europe. The program is aimed at identifying curative therapies for mantle cell lymphoma. Because mantle cell lymphoma is a form of lymphoma for which treatment options have been limited and survival much too short, this intensive and aggressive research effort is critically important.

#### THE BURDEN OF LYMPHOMA AND NEED FOR NEW TREATMENTS

Lymphoma is the most commonly diagnosed hematologic cancer and the third most common childhood cancer. Although lymphoma experts hail the lymphoma

therapeutic advances of the last decade for dramatically changing lymphoma treatment and care, these new treatments do not eliminate the pressing need for additional therapeutic research. The numbers underscore the need for a continued commitment to lymphoma research. In 2007, approximately 71,380 Americans will be diagnosed with lymphoma. It is estimated that 63,190 will be diagnosed with non-Hodgkin lymphoma (NHL), and that 18,660 will die from NHL. Also in 2007, it is expected that 8,190 cases of Hodgkin lymphoma will be diagnosed, and 1,070 Americans will die from the disease. Nearly half a million Americans are living with lymphoma.

The treatment advances of recent years have not boosted the survival rate for NHL as dramatically as we had hoped. The 5-year survival rate is 63 percent and the 10-year survival rate is only 49 percent. The 5-year survival rate for Hodgkin lymphoma is 86 percent and the 10-year survival rate is 81 percent.

Still another issue must be remembered when we are evaluating the progress that has been made in the fight against Hodgkin lymphoma and NHL. There is an increasing body of knowledge about the long-term effects of treatment for cancer, but there is a need for additional research to understand the effects of cancer therapies, develop strategies to minimize or address these effects, and develop therapies that are accompanied by fewer side effects. A study published in a recent edition of the *Journal of the National Cancer Institute* underscored the challenges facing Hodgkin lymphoma patients; according to the report of a British research team, Hodgkin lymphoma patients may have an increased rate of myocardial infarction for up to 25 years after undergoing treatment. The cardiotoxicity can be attributed to the radiotherapy, anthracyclines, and vincristine used in Hodgkin lymphoma therapy.

#### ADVANCES IN LYMPHOMA RESEARCH

In the last decade, there have been a number of significant advances in lymphoma research that have contributed to deeper understanding of the disease and its progression and fostered the development of new treatments. Knowledge about the diversity of lymphoma has contributed to the effort to target treatment regimens to specific forms of the disease. In addition, we are learning more about the link between environmental factors and infections—chemicals, toxins, drugs, infectious agents such as hepatitis C and Epstein Barr virus, and the gastric pathogen *Helicobacter pylori*—and many forms of lymphoma.

Recent lymphoma treatment advances are a monoclonal antibody (rituximab) that blocks a specific protein on B lymphocytes and a radioactively labeled monoclonal antibody (tositumomab) that may prolong remission in follicular lymphoma patients. Studies suggest that bortezomib, which inhibits an enzyme complex that plays a role in regulating cell function and growth, will shrink tumors in patients with mantle cell lymphoma. Finally, research is underway on additional immunotherapies, including therapeutic vaccines for lymphoma.

One of the key areas of inquiry is the identification of the best combinations of treatments, including rituximab. Investigators are also considering whether to treat low-grade follicular lymphoma immediately or to continue the current approach of “watch and wait.” Stem cell transplantation remains an important part of lymphoma treatment, but additional research may contribute to refinements in the procedure and better results for lymphoma patients.

There are a number of new therapies in development with the hope of prolonging life and providing a better quality of life. In addition, long-term and late effects of treatment are a concern. Lymphoma patients may be at risk for developing second cancers, and investigation of these risks is critical and may contribute to better management of currently available therapies.

#### ROLE OF LRF IN LYMPHOMA RESEARCH

By supporting outstanding investigators considering a wide range of topics in lymphoma research, LRF contributes significantly to progress in the field. In 2003, LRF made a determination that it would tackle one of the most challenging forms of non-Hodgkin lymphoma, mantle cell lymphoma, with an aggressive and well-coordinated research program that focuses on this rare form of non-Hodgkin lymphoma (NHL) affecting only 6–10 percent of NHL patients.

Since 2003, LRF has dedicated more than \$21 million to the Mantle Cell Lymphoma Research Initiative, and with those funds has supported a range of critical research efforts, including:

- Hosting the preeminent scientific meeting focused exclusively on mantle cell lymphoma.
- Formation of the Mantle Cell Lymphoma Consortium to stimulate collaboration among its members to accelerate the pace of finding cures for the disease.

—Launching of an MCL web site and awarding the first set of correlative clinical trials grants.

—Inclusion of nearly 100 scientists in the network of mantle cell researchers.

The Mantle Cell Lymphoma Consortium may serve as a research model for focusing on other forms of lymphoma, and LRF is moving ahead with additional targeted initiatives.

#### ROLE OF NIH IN LYMPHOMA RESEARCH

LRF will continue to play a strong and creative role in funding lymphoma research, fostering cutting edge initiatives that hold the promise of making a meaningful and positive change in the lives of those living with lymphoma. Although the Foundation's efforts will continue and even expand, its work must be undertaken in collaboration with NIH. This is not only because of the magnitude of the NIH cancer research budget but also because of the potential for NIH to provide leadership among all elements of the research and development community, including NIH intramural researchers, academic researchers, private foundations, industry, and the Food and Drug Administration (FDA).

We understand that the substantial increases in NIH funding that Congress approved between 1999 and 2003 will not be replicated in the foreseeable future. However, we urge that Congress provide an increase of 6.7 percent for NIH in fiscal year 2008, an increase that will simply protect the recent investment in NIH and permit additional research progress. Advances in cancer research have contributed to improvements in survival, but these advances have generally been incremental and have required a sustained funding commitment.

We urge that Congress protect NIH funding and strive to provide an increase in funding to allow researchers to pursue promising avenues of research. LRF recommends that NIH strengthen its lymphoma research program by several actions:

- The National Cancer Institute (NCI) should boost its support for translational and clinical lymphoma research. NCI should support research efforts aimed at evaluating the most appropriate utilization of new therapies, including the best possible combinations of therapies.
- NCI should also enhance its support for correlative studies of tumor biology and treatment response, as well as its investment in research on the late and long-term effects of lymphoma treatments.
- NCI should expand its research effort focused on understanding the complex interaction among environmental, viral, and immunogenetic factors that are involved in the initiation and promotion of lymphoma.
- Although NCI has historically been the lead institute in funding lymphoma research, other institutes, including the National Heart, Lung, and Blood Institute (NHLBI), National Institute on Aging (NIA), and National Institute of Environmental Health Sciences (NIEHS), should also evaluate and improve their lymphoma research programs. A lymphoma-focused initiative to investigate environmental/viral links is warranted.

NCI is developing a plan for the implementation of the recommendations of its Clinical Trials Working Group. To date, most implementation efforts have concentrated on the planning and management of NCI-sponsored clinical trials. We urge NCI to act on recommendations of the Working Group that focused on strengthening patient participation in clinical trials. Increasing the rate of participation in clinical trials is a key element in accelerating the pace of cancer clinical research and the development of new treatments.

We also recommend that NCI consider actions that would encourage the utilization of a centralized institutional review board (IRB), an effort that could contribute to a streamlining of the review of new clinical trials and minimize delays in the clinical trials process. NCI has tested a central IRB, and that IRB or another might be utilized by cancer researchers for review and approval of their protocols. Encouragement from NCI regarding the utilization of a centralized IRB could contribute to a more rapid acceptance among researchers.

We have detailed some impressive advances in lymphoma treatment, but the research task is far from complete. Much more research must be undertaken to ensure proper utilization of existing therapies, and new therapies are needed for a number of different forms of lymphoma. We look forward to the continued commitment of Congress to lymphoma research. As we seek to strengthen our private sector investment in research, we hope that the public-private lymphoma research partnership will continue.

## PREPARED STATEMENT OF THE MARCH OF DIMES FOUNDATION

The 3 million volunteers and 1,400 staff members of the March of Dimes Foundation appreciate the opportunity to submit the Foundation's Federal funding recommendations for fiscal year 2008. The March of Dimes is a national voluntary health agency working to improve the health of mothers, infants and children by preventing birth defects, premature birth and infant mortality through research, community services, education, and advocacy.

The volunteers and staff of the March of Dimes urge the subcommittee to provide the funding increases recommended below. Of particular note, one of the last actions of the 109th Congress was unanimous approval of the PREEMIE Act (Public Law 109-450). The March of Dimes commends Congress for recognizing the growing health crisis of preterm birth and calls on the subcommittee to fund two major provisions of the act: (1) expansion of CDC activities related to preterm birth, which are outlined in the CDC section of this testimony and (2) a Surgeon General's Conference and report on preterm birth. In order to convene a Surgeon General's conference on preterm birth and produce a widely disseminated report, \$1,000,000 in fiscal year 2008 funding is needed. The conference and report will establish a public-private research and education agenda to accelerate the development of new strategies for preventing preterm birth.

## NATIONAL INSTITUTES OF HEALTH (NIH)

The March of Dimes joins the larger research community in recommending a 6.7 percent increase in funding for the NIH bringing total Federal support to just over \$30 billion. The 6.7 percent increase was calculated by the biomedical inflator of 3.7 percent and lost purchasing power which is 3 percent. Since the doubling of NIH's budget was completed in 2003, the agency has lost 13 percent of its purchasing power. With all the threats to children's health it is imperative to increase the overall investment in medical research.

*Office of the Director*

The March of Dimes was extremely pleased that Congress included \$69 million for the National Children's Study (NCS) in the fiscal year 2007 Joint Funding Resolution, allowing for implementation of the next phase of the study. The Foundation urges the subcommittee to include within the Office of the Director \$111 million (\$42 million in new funding) for the NCS in fiscal year 2008. While the amount may seem substantial, it is dwarfed by the cost of treating the diseases and conditions the study is designed to address. Approximately 1 year after the full study is underway researchers will begin a thorough review of data pertaining to premature birth and pregnancy outcomes and, using this data, will focus on an array of serious pediatric health problems. This landmark study holds the potential to dramatically enhance understanding of the causes of preterm birth, birth defects, and infant mortality as well as numerous other childhood diseases and conditions.

*National Institute of Child Health and Human Development (NICHD)*

The March of Dimes recommends a 6.7 percent increase for NICHD in fiscal year 2008 and an increase of at least \$100 million over the next 5 years to boost prematurity-related research. In recent years, the NICHD has made a major commitment to enhance our understanding of the factors that result in premature birth and to develop strategies to prolong pregnancy so that infants are not born too soon. But additional research is needed.

Since 1981, the preterm birth rate has increased 30 percent resulting in more than half a million premature births in 2005—or 1 in 8. Preterm birth is the leading cause of death in the first month of life and, for those babies who do survive, 1 in 5 experience life long health problems including cerebral palsy, mental retardation, chronic lung disease, and vision and hearing loss. Preterm labor can happen to any pregnant woman, and the causes of nearly half of all premature births are not yet known.

This growing problem of preterm births was brought into sharp focus by the 2006 Institute of Medicine (IOM) report entitled, "Preterm Birth: Causes, Consequences and Prevention." The IOM found that the annual economic burden associated with preterm birth in the United States was at least \$26.2 billion, or \$51,600 per infant born preterm. In 2003, the national hospital bill alone for the care of these babies exceeded \$18 billion, half of which was borne by Medicaid and other public programs and the remainder was charged to employers and families.

*Safe Motherhood/Infant Health*

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health. The March of Dimes recommends an \$8 million increase, as authorized in the PREEMIE Act, for CDC to increase epidemiological research on preterm labor and delivery, which is vital to ultimately preventing preterm birth.

Specifically, these additional funds will enable CDC to conduct additional epidemiological studies on preterm birth, including the relationship between prematurity, birth defects and developmental disabilities. These new funds will also make possible the establishment of systems for the collection of maternal-infant clinical and biomedical information that is linked with the Pregnancy Risk Assessment Monitoring System (PRAMS). Increasing CDC's research activities related to preterm birth will bring the Nation closer to improving screening and early detection and finding new interventions for women at risk for preterm labor.

*National Center on Birth Defects and Developmental Disabilities (NCBDDD)*

Of particular interest to the March of Dimes is NCBDDD's birth defects program that includes surveillance, research and prevention activities. For fiscal year 2008, the March of Dimes requests an increase of \$10 million to support surveillance and research and an additional \$2 million for folic acid education. In the March of Dimes professional judgment, these modest increases are vital to making progress in reducing the incidence of birth defects.

In the United States, about 3 percent of all babies are born with a major birth defect. Birth defects are the leading cause of infant mortality accounting for more than 20 percent of all infant deaths every year. Children with birth defects who survive may experience lifelong physical and mental disabilities, and are at increased risk for developing other health problems. In fact, birth defects contribute substantially to the Nation's health care costs. According to CDC, the lifetime economic cost of caring for infants born each year with 1 of the 18 most common birth defects exceeds \$8 billion.

The causes of nearly 70 percent of birth defects are unknown and it is therefore critical that the subcommittee increase funding for the National Birth Defects Prevention Study. This groundbreaking CDC initiative is being carried out by 9 regional Centers for Birth Defects Research and Prevention located in Arkansas, California, Georgia, Iowa, Massachusetts, New York, North Carolina, Texas, and Utah. Each of these centers identify infants with major birth defects; interview mothers about medical history, environmental exposures, and lifestyle before and during pregnancy; and collect DNA samples to study gene-environment interactions. This study has nearly 11 years worth of data and DNA samples collected. Due to funding limitations, CDC has yet to be able to analyze the DNA samples to identify genetic risk factors. In addition, without increased funding the CDC will be forced to decrease the number of centers participating in the study.

NCBDDD also provides funding to assist States with community-based birth defects tracking systems, programs to prevent birth defects and improve access to health services for children with birth defects. Surveillance forms the backbone of a vital, functional and responsive public health network. Additional resources are sorely needed to help States seeking assistance.

Finally, NCBDDD is conducting a national public and health professions education campaign designed to increase the number of women taking folic acid. CDC estimates that up to 70 percent of neural tube defects (NTDs), serious birth defects of the brain and spinal cord including anencephaly and spina bifida could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily, beginning before pregnancy. Since 1996, the rate of NTDs in the United States has decreased by 26 percent. Unfortunately, according to a recent analysis conducted by CDC folate concentrations among non-pregnant women of child bearing age decreased by 16 percent from 1999–2000 through 2003–2004. Clearly, women are still not receiving an adequate level of folic acid and increased resources to CDC for the expansion of its folic acid education campaign is needed.

*National Center for Health Statistics*

The National Center for Health Statistics (NCHS) provides data essential for both public and private research and programmatic initiatives. The National Vital Statistics System and the National Survey on Family Growth, for example, is the principal source of information on the utilization of prenatal care and on birth outcomes, including preterm delivery, low birthweight and infant mortality. The current funding level threatens the collection of vital information and more specifically NCHS

lacks the resources to collect a full year's worth of vital statistics from States. Without at least \$3 million in additional funding we will become the first industrialized Nation unable to collect birth, death and other vital statistics. The March of Dimes supports a funding level of \$117 million, an increase of \$8 million over fiscal year 2007, to ensure that NCHS continues its role in monitoring our Nation's health.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

##### *Newborn Screening*

Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal and functional conditions in newborns. Screening detects disorders in newborns that, if left untreated, can cause death, disability, mental retardation and other serious illnesses. Parents are often unaware that while nearly all babies born in the United States undergo newborn screening for genetic birth defects, the number and quality of these tests vary from State to State. The March of Dimes, the American Academy of Pediatrics and the American College of Medical Genetics recommend that at a minimum, every baby born in the United States be screened for a core group of 29 treatable conditions regardless of the State in which the infant is born. Only 11 States and the District of Columbia currently screen for all 29 of these conditions.

Currently, Federal support for State newborn screening activities is provided through the Maternal and Child Health Block Grant, Special Projects of Regional and National Significance (SPRANS). The March of Dimes recommends full funding of the MCH Block Grant at the authorized level of \$850 million. In addition, the Foundation urges that \$9 million of SPRANS funding be set-aside for newborn screening activities (an increase of \$3 million over fiscal year 2007). In the March of Dimes professional judgment, this funding will allow for the continuation of the Regional Genetic Service and Newborn Screening Collaboratives that focus on the maldistribution of genetic services and resources and bring services closer to local communities. It would also enable HRSA to improve the capacity of States to: (1) provide screening, counseling, testing, and special services for newborns and children at risk for heritable disorders; (2) educate health professionals and parents on the availability and importance of newborn screening; and (3) support States with technical assistance on the acquisition and use of new technologies and newborn screening services.

#### FISCAL YEAR 2008 FEDERAL FUNDING RECOMMENDATIONS

[In millions of dollars]

Program	Fiscal year 2007 funding	March of Dimes fiscal year 2008 rec- ommendation
National Institutes of Health (Total) .....	28,879	30,813
National Children's Study .....	69	111
National Institute of Child Health & Human Development .....	1,253	1,337
National Human Genome Research Institute .....	486	519
National Center on Minority Health and Disparities .....	199	212
Center for Disease Control and Prevention (CDC) .....	6,095	7,800
Save Motherhood/Infant Health (NCCDPHP) .....	44	52
Birth Defects Research & Surveillance .....	15	25
Folic Acid Education Campaign .....	2	4
Immunization .....	520	802.4
Polio Eradication .....	101	101
National Center for Health Statistics .....	109	117
Health Resources and Services Administration (Total) .....	6,884	7,500
Maternal and Child Health Block Grant .....	693	850
Newborn Screening .....	6	9
Newborn Hearing Screening .....	10	10
Consolidated (Community) Health Centers .....	1,988	2,188
Healthy Start .....	102	102
Agency for Healthcare Research and Quality .....	319	350

## PREPARED STATEMENT OF MEHARRY MEDICAL COLLEGE

## SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

\$300 million for the Title VII Health Professions Training programs, including:  
 —\$33.6 million for the Minority Centers of Excellence.  
 —\$35.6 million for the Health Careers Opportunity program.  
 \$250 million for the National Institutes of Health's National Center on Minority Health and Health Disparities.  
 \$169 million for the National Center for Research Resources Extramural Facilities Construction program.  
 —\$6.7 percent increase for Research Centers for Minority Institutions.  
 —\$119 million for Extramural Facilities construction.  
 \$65 million for the Department of Health and Human Services' Office of Minority Health.  
 \$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions program.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, president and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. I want to say that minority health professional institutions and the Title VII Health Professions Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. If you take minorities as a whole, Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15 percent of the U.S. population while only 2–3 percent of the Nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the

underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 and fiscal year 2007 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Morehouse School of Medicine, a historically black medical school in Atlanta. I give credit to my career in academia, and my being here today, to Title VII Health Profession Training programs' Faculty Loan Repayment Program. Without that program, I would not be the president of my father's alma mater, Meharry Medical College, another historically black medical school dedicated to eliminating healthcare disparities through education, research and culturally relevant patient care.

In fiscal year 2008, funding for the Title VII Health Professions Training programs must be restored to the fiscal year 2005 level of \$300 million, with two programs—the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs)—in particular need of a funding restoration. In addition, the National Institutes of Health (NIH)'s National Center on Minority Health and Health Disparities (NCMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), are both in need of a funding increase.

#### MINORITY CENTERS OF EXCELLENCE

COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs.

Presently the statute is configured in such a way that the "original four" institutions compete for the first \$12 million in funding, "Hispanic and Native American" institutions compete for the next \$12 million, and "Other" institutions can compete for grants when the overall funding is above \$24 million. For funding above \$30 million all eligible institutions can compete for funding.

However, as a consequence of limited funding for COEs in fiscal year 2006 and fiscal year 2007, "Hispanic and Native American" and "Other" COEs have lost their support. Out of 34 total COEs in fiscal year 2005, only 4 now remain due to the cuts in funding.

For fiscal year 2008, I recommend a funding level of \$33.6 million for COEs.

#### HEALTH CAREERS OPPORTUNITY PROGRAM (HCOP)

HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. If HCOPs continue to lose Federal support, then these numbers will drastically decrease. It is estimated that the number of minority students admitted to health professional schools will drop by 25–50 percent without HCOPs. A reduction of just 25 percent in the number of minority students admitted to medical school will produce approximately 600 fewer minority medical students nationwide.

As a result of cuts in the fiscal year 2006 and fiscal year 2007 Labor-HHS Appropriations process, only 4 out of 74 total HCOPs currently receive Federal funding. As president of Meharry, I feel this loss as we were one of the 70 institutions who lost their HCOP grants.

For fiscal year 2008, I recommend a funding level of \$35.6 million for HCOPs.

#### NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES CONSTRUCTION

Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our Nation's research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is \$250 million. The law also includes a 25 percent set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. Finally, the law allows the NCRR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools.

Unfortunately, funding for NCRR's Extramural Facility Construction program was completely eliminated in the fiscal year 2006 Labor-HHS bill, and no funding was restored in the funding resolution for fiscal year 2007. In fiscal year 2008, please restore funding for this program to its fiscal year 2004 level of \$119 million, or at a minimum, provide funding equal to the fiscal year 2005 appropriation of \$40 million.

#### RESEARCH CENTERS IN MINORITY INSTITUTIONS

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2008.

#### STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS—DEPARTMENT OF EDUCATION

The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2008, an appropriation of \$65 million (an increase of \$7 million over fiscal year 2007) is suggested to continue the vital support that this program provides to historically black graduate institutions.

#### *National Center on Minority Health and Health Disparities*

The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NCMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NCMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NCMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Minority Centers of Excellence program.

For fiscal year 2008, I recommend a funding level of \$250 million for the NCMHD.

#### *Department of Health and Human Services' Office of Minority Health (OMH)*

Specific programs at OMH include:

- (1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
- (2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
- (3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
- (4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. Unfortunately, the OMH does not yet have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations.

For fiscal year 2008, I recommend a funding level of \$65 million for the OMH. Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Meharry Medical College along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. Meharry and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have done for 1,876.

Thank you, Mr. Chairman, for this opportunity.

#### PREPARED STATEMENT OF THE MOREHOUSE SCHOOL OF MEDICINE

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Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. John E. Maupin, president of Morehouse School of Medicine (MSM) in Atlanta, Georgia. I have previously served as President of Meharry Medical College, executive vice-president at Morehouse School of Medicine, as director of a community health center in Atlanta, and deputy director of health in Baltimore, Maryland. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Morehouse is a private school with a very public mission of educating students from traditionally underserved communities so that they will care for the underserved. Mr. Chairman, I would like to share with you how your committee can help us continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural

and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals, like MSM, have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 and fiscal year 2007 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Meharry Medical College, a historically black medical and dental school in Nashville, Tennessee. I have seen first hand what Title VII funds have done to minority serving institutions like Morehouse and Meharry. I compare my days as a student to my days as president, without that Title VII, our institutions would not be here today. However, Mr. Chairman, since those funds have been cut in the last 2 fiscal years, we are standing at a cross roads. This committee has the power to decide if our institutions will go forward and thrive, or if we will continue to try to just survive. We want to work with you to eliminate health disparities and produce world class professionals, but we need your assistance.

In fiscal year 2008, funding for the Title VII Health Professions Training programs must be restored to the fiscal year 2005 level of \$300 million, with two programs—the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs)—in particular need of a funding restoration. In addition, the National Institutes of Health (NIH)'s National Center on Minority Health and Health Disparities (NCMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), are both in need of a funding increase.

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Presently the statute is configured in such a way that the "original four" institutions compete for the first \$12 million in funding, "Hispanic and Native American" institutions compete for the next \$12 million, and "Other" institutions can compete for grants when the overall funding is above \$24 million. For funding above \$30 million all eligible institutions can compete for funding.

However, as a consequence of limited funding for COEs in fiscal year 2006 and fiscal year 2007, "Hispanic and Native American" and "Other" COEs have lost their support. Out of 34 total COEs in fiscal year 2005, only 4 now remain due to the cuts in funding. MSM lost its COE funding as well, which was a devastating blow to our School.

For fiscal year 2008, I recommend a funding level of \$33.6 million for COEs.

#### HEALTH CAREERS OPPORTUNITY PROGRAM (HCOP)

HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary

schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. If HCOPs continue to lose Federal support, then these numbers will drastically decrease. It is estimated that the number of minority students admitted to health professional schools will drop by 25–50 percent without HCOPs. A reduction of just 25 percent in the number of minority students admitted to medical school will produce approximately 600 fewer minority medical students nationwide.

As a result of cuts in the fiscal year 2006 and fiscal year 2007 Labor-HHS Appropriations process, only 4 out of 74 total HCOPs currently receive Federal funding. As president of MSM, I am proud to say we competed well enough to be one of those four; however, those who have the same mission as ours must have this funding as well.

For fiscal year 2008, I recommend a funding level of \$35.6 million for HCOPs.

#### NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES CONSTRUCTION

Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our Nation's research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is \$250 million. The law also includes a 25 percent set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. Finally, the law allows the NCRR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools.

Unfortunately, funding for NCRR's Extramural Facility Construction program was completely eliminated in the fiscal year 2006 Labor-HHS bill, and no funding was restored in the funding resolution for fiscal year 2007. In fiscal year 2008, please restore funding for this program to its fiscal year 2004 level of \$119 million, or at a minimum, provide funding equal to the fiscal year 2005 appropriation of \$40 million.

#### RESEARCH CENTERS IN MINORITY INSTITUTIONS

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2008.

#### STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS—DEPARTMENT OF EDUCATION

The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2008, an appropriation of \$65 million (an increase of \$7 million over fiscal year 2007) is suggested to continue the vital support that this program provides to historically black graduate institutions.

#### *National Center on Minority Health and Health Disparities*

The National Center on Minority Health and Health Disparities (NCMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NCMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NCMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NCMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Minority Centers of Excellence program.

For fiscal year 2008, I recommend a funding level of \$250 million for the NCMHD.  
*Department of Health and Human Services' Office of Minority Health (OMH)*

Specific programs at OMH include:

- (1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
- (2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
- (3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
- (4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. Unfortunately, the OMH does not yet have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations.

For fiscal year 2008, I recommend a funding level of \$65 million for the OMH.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Morehouse School of Medicine along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. MSM and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have since our founding day.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

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#### PREPARED STATEMENT OF THE NATIONAL ALLIANCE TO END HOMELESSNESS

The National Alliance to End Homelessness (the Alliance) is a nonpartisan, non-profit organization that has several thousand partner agencies and organizations across the country. These partners are local faith-based and community-based non-profit organizations and public sector agencies that provide homeless people with shelter, transitional and permanent housing, and services such as substance abuse treatment, job training, and physical health and mental health care. In addition, we have supported over 160 State and local entities who have completed 10 year plans to end homelessness. The Alliance represents a united effort to address the root causes of homelessness and challenge society's acceptance of homelessness as an inevitable by-product of American life.

Overview—Our recent research report, *Homelessness Counts*, estimates that 744,313 people are homeless on any given night. This includes 98,452 families. Fifty-six percent of the total were living in shelters or transitional housing and 44 percent were unsheltered. This report illustrates that far too many people are homeless and many are not being reached by existing programs. This is inexcusable given that we know what interventions work and several communities are making progress toward ending homelessness. These interventions, such as housing first for families and permanent supportive housing, couple housing with an appropriate level of services for the family or individual. Therefore, not only does the Department of Housing and Urban Development play a role in ending homelessness, so do the Departments of Labor, Health and Human Services, and Education. We call on Congress and all Federal agencies to adequately fund the programs that assist States and local entities in developing permanent housing and the necessary social services to once and for all end homelessness for all Americans.

#### GOALS

1. *Moving Forward to End Homelessness.*—Communities across America are working toward ending homelessness. Communities are using Federal, State, and local funds to help homeless persons maintain housing. It is important that this progress not be undermined. To this end, the Alliance recommends the following:

- Allocate an additional \$80 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services.
- Increase funding to Projects for Assistance in Transition from Homelessness (PATH) to \$58.3 million.
- Increase the Runaway and Homeless Youth Act Programs to \$140 million.

- Provide a \$200 million increase in the Community Health Center program within Health Resource Services Administration. This would result in the Health Care for the Homeless programs receiving \$190 million.
- Fund Education for Homeless Children and Youth services at its full authorized level of \$70 million.
- Increase funding for the Homeless Veterans Reintegration Program to \$50 million.
- 2. *Connecting Homeless Families, Individuals, and Youth to Mainstream Services.*—People experiencing homelessness also depend on mainstream programs such as the ones below to live day to day and once housed, remain housed. The Alliance recommends the following to meet this goal:
  - Fund the Social Services Block Grant at \$1.7 billion, the same funding level as fiscal year 2006.
  - Reject cuts and fund the Community Services Block Grant at \$700 million
  - Appropriate \$60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program.

#### GOAL 1—MOVING FORWARD TO END HOMELESSNESS

##### *Support Services for Permanent Supportive Housing Projects*

The Alliance recommends allocating an additional \$80 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services. The administration has set a goal of ending chronic homelessness by 2012 and joined with Congress to set a goal of creating 150,000 additional units of permanent supportive housing. According to the Alliance's report, Homelessness Counts, 23 percent of those who are homeless on any given night meet the chronic homelessness definition of being homeless for long periods of time or repeatedly. These people need access to housing and support services. The Alliance and our partners believe the Department of Health and Human Services needs to raise its commitment to provide the services necessary to end homelessness. Therefore, we are proposing this increase in SAMHSA funding to help communities provide services to 16,000 new units of permanent supportive housing.

#### PROJECTS FOR TRANSITION ASSISTANCE FROM HOMELESSNESS (PATH)

The Alliance recommends that Congress increase PATH funding to \$58.3 million and adjust the funding formula to increase allocation for small States and territories.

The PATH program provides access to mental health services for homeless people with serious mental illnesses. PATH focuses on outreach to eligible consumers, followed by help in ensuring that those consumers are connected with mainstream services, such as Supplemental Security Income (SSI), Medicaid and welfare programs. Under the PATH formula grant, approximately 30 States share in the program's annual appropriations increases. The remaining States and territories receive the minimum grant of \$300,000 for States and \$50,000 for territories. These amounts have not been raised since the program was authorized in 1991. To account for inflation, the minimum allocation should be raised to \$600,000 for States and \$100,000 for territories. Amending the minimum allocation requires a legislative change. If the authorizing committees do not address this issue, we hope that appropriators will explore ways to make the change through appropriations bill language.

#### RUNAWAY AND HOMELESS YOUTH PROGRAMS

The Alliance recommends funding the Runaway and Homeless Youth Act (RHYA) programs at \$140 million. RHYA programs support cost-effective, community and faith-based organizations that protect youth from the harms of life on the streets. The problems of homeless and runaway youth are addressed by the Administration for Children and Families within HHS, which operates coordinated competitive grant programs like RHYA. The RHYA programs can either reunify youth safely with family or find alternative living arrangements. RHYA programs end homelessness by: engaging youth living on the street with Street Outreach Programs, quickly providing emergency shelter and family crisis counseling through the Basic Centers, or providing supportive housing that helps young people develop lifelong independent living skills through Transitional Living Programs. Recently, the Congressional Research Service issued a report complimenting the good work of RHYA programs but detailing the gaps in services due to limited funding. It is essential that Congress increase this program.

## COMMUNITY HEALTH CENTERS AND HEALTH CARE FOR THE HOMELESS (HCH) PROGRAMS

The Alliance recommends a \$200 million increase to the Community Health Centers Program which would result in funding the HCH programs at \$190 million.

Persons living on the street suffer from health problems resulting from or exacerbated by the condition of being homeless, such as hypothermia, frostbite, and heat-stroke. In addition, they often have infections of the respiratory and gastrointestinal systems, tuberculosis, vascular diseases such as leg ulcers, and hypertension.<sup>1</sup> Health care for the homeless programs are vital to prevent these conditions from becoming fatal. Congress allocates 8.7 percent of the Consolidated Health Centers account for Health Care for the Homeless (HCH) projects. The HCH program has achieved significant success since its inception in 1987, but the health care needs of Americans experiencing homelessness each year far exceed the service capacity of Health Care for the Homeless grantees.

## EDUCATION FOR HOMELESS CHILDREN AND YOUTH

The Alliance recommends funding Education for Homeless Children and Youth (EHCY) at its full authorized level of \$70 million. The most important potential source of stability for homeless children is school. The mission of the Education for Homeless Children and Youth program is to ensure that these children can continue to attend school and thrive. The Education for Homeless Children and Youth program, within the Department of Education's Office of Elementary and Secondary Education, removes obstacles to enrollment and retention by establishing liaisons between schools and shelters and providing funding for transportation, tutoring, school supplies, and the coordination of statewide efforts to remove barriers.

## HOMELESS VETERANS REINTEGRATION PROGRAM (HVRP)

The Alliance recommends that Congress increase HVRP funding to \$50 million.

HVRP, within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer outreach, job placement, and supportive services to homeless veterans. HVRP is the primary employment services program accessible by homeless veterans and the only targeted employment program for any homeless subpopulation. It is estimated that this program only reaches about two percent of the overall homeless veteran population. An appropriation at the authorized level of \$50 million would enable HVRP grantees to reach approximately 19,866 homeless veterans.

## GOAL 2—CONNECTING HOMELESS FAMILIES, INDIVIDUALS AND YOUTH TO MAINSTREAM SERVICES

*Social Services Block Grant (SSBG)*

The Alliance recommends that Congress fully restore SSBG funding to its fiscal year 2006 level of \$1.7 billion. SSBG funds are essential for programs dedicated to ending homelessness. In particular, youth housing programs and permanent supportive housing providers often receive State, county, and local funds which originate from the SSBG. As the U.S. Department of Housing and Urban Development has focused its funding on housing, programs that provide both housing and social services have struggled to fund the service component of their programs. This gap is often closed using Federal programs such as SSBG.

*Community Services Block Grant (CSBG)*

The Alliance recommends that Congress fully restore CSBG funding to its fiscal year 2006 level of \$630 million. Funding cuts for the CSBG will destabilize the progress communities have made toward ending homelessness by not only ending services directly provided by CSBG funds but limiting a community's ability to access other Federal dollars such as those provided by HUD. Community Action Agencies (CAAs) are directly involved in housing and homelessness services. In several communities, CAAs lead the Continuum of Care (CoC). CoCs coordinate local homeless service providers and the community's McKinney-Vento Homeless Assistance Grant application process with the Department of Housing and Urban Development.

In the fiscal year 2004 Community Services Block Grant Information Systems report published by the U.S. Department of Health and Human Services, CAAs reported administering \$207.4 million in section 8 vouchers, \$30 million in section 202

<sup>1</sup> Harris, Shirley N, Carol T. Mowbray and Andrea Solarz. Physical Health, Mental Health and Substance Abuse Problems of Shelter Users. Health and Social Work, Vol. 19, 1994.

services<sup>2</sup> and \$271.1 million in other Department of Housing and Urban Development (HUD) programs which includes homeless program funding.<sup>3</sup>

*Foster Youth Education and Training Vouchers*

The Alliance recommends that Congress appropriate \$60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program. The Education and Training Voucher Program offers funds to foster youth and former foster youth to enable them to attend colleges, universities and vocational training institutions. Students may receive up to \$5,000 a year for college or vocational training education. The funds may be used for tuition, books, housing, or other qualified living expenses. Given the large number of people experiencing homelessness who have a foster care history, it is important to provide assistance such as these education and training vouchers to stabilize youth, prevent economic crisis, and prevent possible homelessness.

CONCLUSION

Homelessness is not inevitable. As communities implement plans to end homelessness, they are struggling to find funding for the services homeless and formerly homeless clients need to maintain housing. The Federal investments in mental health services, substance abuse treatment, employment training, youth housing, and case management discussed above will help communities create stable housing programs and change social systems which will end homelessness for millions of Americans.

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PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH (NAEVR)

EXECUTIVE SUMMARY

NAEVR requests fiscal year 2008 NIH funding at \$31 billion, or a 6.7 percent increase over fiscal year 2007, to balance the biomedical inflation rate of 3.7 percent and to maintain the momentum of discovery. Although NAEVR commends the leadership's actions in the 110th Congress to increase fiscal year 2007 NIH funding by \$620 million, this was just an initial step in restoring the NIH's purchasing power, which has declined by more than 13 percent since fiscal year 2005. That power would be eroded even further under the President's proposed fiscal year 2008 budget. NAEVR commends NIH Director Dr. Zerhouni who has articulately described his agenda to foster collaborative, cost-effective research and to transform the healthcare research and delivery paradigm into one that is predictive, preemptive, preventive, and personalized. NIH is the world's premier institution and must be adequately funded so that its research can reduce healthcare costs, increase productivity, improve quality of life, and ensure our Nation's global competitiveness.

NAEVR requests that Congress make vision health a top priority by funding the NEI at \$711 million in fiscal year 2008, or a 6.7 percent increase over fiscal year 2007. This level is necessary to fully advance the breakthroughs resulting from NEI's basic and clinical research that are resulting in treatments and therapies to prevent eye disease and restore vision. Vision impairment/eye disease is a major public health problem that is growing and which disproportionately affects the aging and minority populations, costing the United States \$68 billion annually in direct and societal costs, let alone reduced independence and quality of life. Adequately funding the NEI is a cost-effective investment in our Nation's health, as it can delay, save, and prevent expenditures, especially to the Medicare and Medicaid programs.

FUNDING THE NEI AT \$711 MILLION IN FISCAL YEAR 2008 ENABLES IT TO LEAD TRANS-INSTITUTE VISION RESEARCH THAT MEETS NIH'S GOAL OF PREEMPTIVE, PREDICTIVE, PREVENTIVE, AND PERSONALIZED HEALTHCARE

Funding NEI at \$711 million in fiscal year 2008 represents the eye and vision research community's judgment as that necessary to fully advance breakthroughs resulting from NEI's basic and clinical research that are resulting in treatments and therapies to prevent eye disease and restore vision.

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<sup>2</sup>Section 202 is dedicated to housing from elderly and disabled individuals and families.

<sup>3</sup>U.S. Department of Health and Human Services, Administration of Children and Families. The Community Services Block Grant fiscal year 2004 Statistical Report. Prepared by the National Association for State Community Services Programs.

NEI research responds to the NIH's overall major health challenges, as set forth by Dr. Zerhouni: an aging population; health disparities; the shift from acute to chronic diseases; and the co-morbid conditions associated with chronic diseases (e.g., diabetic retinopathy as a result of the epidemic of diabetes). In describing the predictive, preemptive, preventive, and personalized approach to healthcare research, Dr. Zerhouni has frequently cited NEI-funded research as tangible examples of the value of our Nation's past and future investment in the NIH. These include:

- Dr. Zerhouni has cited as a breakthrough the collaborative Human Genome Project/NEI-funded discovery of gene variants strongly associated with an individual's risk of developing age-related macular degeneration (AMD), the leading cause of blindness (affecting more than 10 million Americans) which increasingly robs seniors of their independence and quality of life. These variants, which are responsible for about 60 percent of the cases of AMD, are associated with the body's inflammatory response and may relate to other inflammation-associated diseases, such as Alzheimer's and Parkinson's disease. As NEI Director Dr. Paul Sieving has stated, "One of the important stories during the next decade will be how Alzheimer's disease and macular degeneration fit together."
- Dr. Zerhouni has cited the NEI-funded Age-Related Eye Disease Study (AREDS) as a cost-effective preventive measure. In 2006, NEI began the second phase of the AREDS study, which will follow up on initial study findings that high levels of dietary zinc and antioxidant vitamins (Vitamins C, E and beta-carotene) are effective in reducing vision loss in people at high risk for developing advanced AMD—by a magnitude of 25 percent.
- NEI has funded research, along with the National Cancer Institute (NCI) and the National Heart, Lung, and Blood Institute (NHLBI), into factors that promote new blood vessel growth (such as Vascular Endothelial Growth Factor, or VEGF). This has resulted in anti-VEGF factors that have been translated into the first generation of ophthalmic drugs approved by the Food and Drug Administration (FDA) to inhibit abnormal blood vessel growth in "wet" AMD, thereby stabilizing vision loss. Current research is focused on using treatments singly and in combination to improve vision or prevent further vision loss due to AMD. As part of its Diabetic Retinopathy Clinical Research Network, NEI is also evaluating these drugs for treatment of macular edema associated with diabetic retinopathy.

Although these breakthroughs came directly from the past doubling of the NIH budget, their long-term potential to preempt, predict, prevent, and treat disease relies on adequately funding NEI's follow-up research. Unless its funding is increased, the NEI's ability to capitalize on the findings cited above will be seriously jeopardized, resulting in "missed opportunities" that could include:

- Following up on the AMD gene discovery by developing diagnostics for early detection and promising therapies, as well as to further study the impact of the body's inflammatory response on other degenerative eye diseases.
- Fully investigating the impact of additional, cost-effective dietary supplements in the AREDS study, singly and in combination, to determine if they can demonstrate enhanced protective effects against progression to advanced AMD.
- Following up with further clinical trials on patients with the "wet" form of AMD, as well as patients with diabetic retinopathy, using the new anti-angiogenic ophthalmic drugs singly and in combination to halt disease progression and potentially restore vision.

In addition, NEI research into other significant eye disease programs, such as glaucoma and cataract, will be threatened, along with quality of life research programs into low vision and chronic dry eye. This comes at a time when the U.S. Census and NEI-funded epidemiological research (also threatened without adequate funding) both cite significant demographic trends that will increase the public health problem of vision impairment and eye disease.

VISION IMPAIRMENT/EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT IS INCREASING HEALTHCARE COSTS, REDUCING PRODUCTIVITY, AND DIMINISHING QUALITY OF LIFE

The 2000 U.S. Census reported that more than 119 million people in the United States were age 40 or older, which is the population most at risk for an age-related eye disease. The NEI estimates that, currently, more than 38 million Americans age 40 and older experience blindness, low vision or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportional

tionate incidence in minority populations and as a co-morbid condition of other chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the United States is \$68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to both the public and private sectors.

In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. As a result, Federal funding for the NEI is a vital investment in the health, and vision health, of our Nation, especially our seniors, as the treatments and therapies emerging from research can preserve and restore vision. Adequately funding the NEI can delay, save, and prevent expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

NAEVR urges fiscal year 2008 NIH and NEI funding at \$31 billion and \$711 million, respectively.

#### ABOUT NAEVR

Founded in 1997, NAEVR is a non-profit advocacy organization comprised of a coalition of 55 professional, consumer, and industry organizations (see list below) involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education about the value and cost-effectiveness of eye and vision research sponsored by the NIH, NEI, and other Federal research entities.

Advanced Medical Optics; Alcon Laboratories, Inc.; Allergan, Inc.; AMD Alliance International; American Academy of Ophthalmology; American Academy of Optometry; American Association for Pediatric Ophthalmology and Strabismus; American Assoc. of Ophthalmic Pathologists; American Diabetes Association; American Glaucoma Society; American Ophthalmological Society; American Society of Retina Specialists; American Optometric Association; American Society of Cataract and Refractive Surgery; American Uveitis Society; Association for Research in Vision and Ophthalmology; Association of Schools and Colleges of Optometry; Association of University Professors of Ophthalmology; Association of Vision Science Librarians; Bausch & Lomb; Blinded Veterans Association; Discovery Eye Foundation; Eli Lilly & Company; Eye Bank Association of America; EyeSight Foundation of Alabama; Fight for Sight; Foundation Fighting Blindness; Genentech, Inc.; Glaucoma Research Foundation; Inspire Pharmaceuticals, Inc.; ISTA Pharmaceuticals, Inc.; Juvenile Diabetes Research Foundation Intl.; Lighthouse International; Lions Clubs Intl. Foundation; Macular Degeneration Partnership; Natl. Vision Rehabilitation Assoc.; Novartis; Ocular Microbiology and Immunology Group; Pfizer Inc.; Prevent Blindness America; Prevention of Blindness Society of Metropolitan Washington; Research to Prevent Blindness; Santen, Inc.; Second Sight; Sjogren's Syndrome Foundation; Tear Film and Ocular Surface Society; The Cornea Society; The Glaucoma Foundation; The Macula Society; The Retina Society; Vision Council of America; Vision Share, The Consortium of Eye Banks; Vistakon, Johnson & Johnson Vision Care, Inc.; Women in Ophthalmology; and Women's Eye Health Task Force.

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#### PREPARED STATEMENT OF THE NATIONAL AREA HEALTH EDUCATION CENTERS ORGANIZATION

##### SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

\$300 million for the Title VII Health Professions Training programs.

\$33 million for area Health Education Centers.

\$4.371 million for Health Education and Training Centers.

The National Area Health Education Centers Organization (NAO) is the professional organization representing Area Health Education Centers (AHECs) and Health Education and Training Centers (HETCs).

AHECs and HETCs are two of the Title VII Health Professions Training programs. The Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce and eliminating the disparities in our Nation's healthcare system. These programs help address healthcare disparities by employing strategies such as providing training for students in rural and underserved areas, interaction with faculty role models

who serve in rural and underserved areas and placement services to foster and encourage students to work in these areas.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They also provide continuing education and other services that improve the quality of community-based healthcare. HETCs use the infrastructure of AHECs to address the needs of diverse populations with persistent and severe unmet health needs. In 5 border and 6 non-border States, HETCs train and support Community Health Workers (CHWs) to provide healthcare services and information to their communities.

Nationwide, AHECs and HETCs support health professional training in almost 25,000 community based practice settings, and over 47,000 health professional students receive training at these sites. Furthermore, over 339,000 health professionals receive continuing education through AHECs and HETCs. AHECs and HETCs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC).

#### COMMUNITY HEALTH CENTERS AND THE NATIONAL HEALTH SERVICE CORPS

CHCs are dedicated to providing preventative and ambulatory healthcare to uninsured and underinsured populations. A March 2006 study published in the *Journal of the American Medical Association (JAMA)* found that CHCs report high percentages of provider vacancies, including an insufficient supply of dentists, pharmacists, pediatricians, family physicians and registered nurses. These shortages are particularly pronounced in CHCs that serve rural areas. Because the Title VII Health Professions Training programs (including AHECs and HETCs) have a successful record of training providers to work in underserved areas, the study recommends increased support for the Title VII Health Professions Training programs as the primary means of alleviating the health professions shortage in rural CHCs. The study serves as an important reminder that the success of CHCs is highly dependent upon a well-trained clinical staff to provide care. Thirty-eight percent of AHEC training sites are CHCs, and 26 percent of the health professionals who receive continuing education through HETCs are employed at CHCs. Another 36 percent are employed at NHSC sites.

AHECs and HETCs also undertake a variety of programs related to the placement and support of NHSC scholars and loan repayment recipients. NHSC scholars and loan repayment recipients commit to practicing in an underserved area, and are focused on improving health by providing comprehensive team-based healthcare that bridges geographic, financial and cultural barriers. As contractors of the NHSC Student/Resident Experiences and Rotations in Community Health (SEARCH) program, AHECs and HETCs help to expand the NHSC by placing students and residents in rotations in rural areas. These students and residents are then far more likely to return to the rural area as a NHSC scholar or loan repayment recipient. This is because health professionals who spend part of their training providing care for rural and underserved populations are 3 to 10 times more likely to practice in rural and underserved areas after graduation or program completion.

#### COMMUNITY HEALTH WORKERS

Like NHSC scholars and loan repayment recipients, CHWs aim to respond to local health problems with effective and culturally sensitive strategies. They provide health services in their communities and specifically address healthcare disparities by working to improve health literacy. CHWs are uniquely suited to these tasks because they come from, and live in, the same communities as their patients. They also speak the same language as their non-English speaking patients.

An October 2006 study by the Health Resources and Services Administration (HRSA) entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" shows the importance of the CHWs. This study found that minority health professionals disproportionately serve minority and other medically underserved populations, minority populations tend to receive better care from practitioners of their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their own language.

HETCs are the only Federal program mandated to recruit, train and support CHWs. In 2004–2005 HETCs provided the initial training and continuing education for over 5,000 CHWs. But the Fiscal Year 2006 and Fiscal Year 2007 Labor-Health and Human Services (HHS)-Education Appropriations bills zeroed out the funding for HETCs. Unless funding is restored, HETCs will no longer be able to recruit, train or support CHWs.

## JUSTIFICATION FOR FUNDING RECOMMENDATIONS

By improving the quality, geographic diversity and diversity of the healthcare workforce, the United States can eliminate healthcare disparities. In order to continue the progress that the Title VII Health Professions Training programs (including AHECs and HETCs) have already made towards this goal, an additional Federal investment is required. NAO recommends that the Title VII Health Professions Training programs are funded at \$300 million in fiscal year 2008, including \$33 million for AHECs and \$4.371 million for HETCs.

## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

The National Association of Children's Hospitals thanks the subcommittee for the opportunity to submit a statement for the hearing record in support of the Children's Hospitals' Graduate Medical Education (CHGME) Program in the Health Resources and Services Administration.

On behalf of the Nation's 60 independent children's teaching hospitals, N.A.C.H. very much appreciates the subcommittee's early commitment to provide Federal GME funding for these hospitals. In 1999, 2000, and 2006, Congress authorized and reauthorized the CHGME program to give independent children's teaching hospitals a level of Federal support for their teaching programs, which seeks to be comparable to what adult teaching hospitals receive from Medicare.

We appreciate very much the continuation of \$297 million for CHGME in the final Fiscal Year 2007 Continuing Resolution, the same level as Congress appropriated for fiscal year 2006. The fiscal year 2007 appropriation marks the first time since Congress first agreed to appropriate \$305 million for CHGME in fiscal year 2004 that the program's funding has not been reduced due to across-the-board spending cuts in health and human services.

*CHGME has Been a Success.*—CHGME support to children's hospitals now approaches about 80 percent of the level of Medicare GME support to adult hospitals. CHGME has made it possible for children's hospitals to strengthen their training of pediatric physicians at a time of national shortages, without having to sacrifice the hospitals' clinical or research programs. And it has enabled the hospitals to achieve strong financial positions, which are essential to their ability to fulfill their capital intensive missions.

For fiscal year 2008, we respectfully request \$330 million, the annual authorization level that Congress enacted and the president signed into law last year. It would make up for the erosion in funding for the CHGME program over the last 4 years and address the cost of inflation. It is important in a program with both wage-related and medical teaching costs. Full funding would ensure the hospitals will have the resources necessary to train and educate the Nation's pediatric workforce.

## N.A.C.H. AND CHILDREN'S HOSPITALS

N.A.C.H. is a not-for-profit trade association, representing more than 135 children's hospitals. They include independent acute care children's hospitals, children's hospitals within larger medical centers, and independent children's specialty and hospitals. N.A.C.H. helps its members fulfill their missions of clinical care, education, research and advocacy for all children.

Children's hospitals are regional and national centers of excellence for children with serious and complex conditions. They are centers of biomedical and health services research for children and are the major training centers for pediatric researchers, as well as a significant number of children's doctors. They also are major safety net providers, serving a disproportionate share of children from low-income families, and they are advocates for the public health of all children.

Although they represent less than 5 percent of all hospitals in the country, the three major types of children's hospitals provide 41 percent of the inpatient care for all children, 42 percent of the inpatient care for children assisted by Medicaid, and most hospital care for children with serious conditions.

## BACKGROUND: THE NEED FOR CHGME

While they account for less than 1 percent of all hospitals, independent children's teaching hospitals alone train 35 percent of all pediatricians, half of all pediatric specialists and the majority of pediatric researchers. They provide required pediatric rotations for many other residents and train more than 4,800 resident FTEs annually. Shortages of pediatric specialists across the Nation only heighten the importance of these hospitals.

Prior to initial funding of the CHGME program for fiscal year 2000, the eligible hospitals were facing enormous challenges to their ability to maintain their training programs. The increasingly price competitive medical marketplace was resulting in more and more payers failing to cover the costs of care, including the costs associated with teaching.

Because they see few if any Medicare patients, independent children's hospitals were essentially left out of Medicare GME, which had become the one major source of GME financing for other teaching hospitals. They received only 1/200th (or less than 0.5 percent) of the Federal GME support that all other teaching hospitals received under Medicare. This lack of GME financing, combined with financial challenges stemming from their other missions, threatened their teaching programs, as well as other services.

*Safety Net Institutions.*—Independent children's hospitals are a significant part of the health care safety net for low-income children, which puts them at financial risk. In fiscal year 2005 children assisted by Medicaid were, on average, 55 percent of all inpatient days of care. Yet, Medicaid average, paid only 78 percent of costs. Without disproportionate share hospital payments, Medicaid would pay even less. Medicaid payment shortfalls for outpatient and physician care are even greater.

The independent children's hospitals also are essential providers of care for seriously and chronically ill children. They devote more than 75 percent of their care to children with one or more chronic or congenital conditions. They provide the majority of inpatient care to children with many serious illnesses—from children with cancer or cerebral palsy, for example, to children needing heart surgery or organ transplants. In some regions, they are the only source of pediatric specialty care. The severity and complexity of illness and the services these institutions must maintain to assure access to this quality care for all children are often poorly reimbursed.

Lastly, many of the independent children's hospitals are a vital part of the emergency and critical care services in their regions. They are part of the emergency response system that must be in place for public health emergencies. Expenses associated with disaster preparedness add to their continuing costs in meeting children's needs.

*Mounting Financial Pressures.*—The CHGME program, and its relatively quick progress to full funding in fiscal year 2002, came at a critical time. In 1997, when Congress first considered establishing CHGME, a growing number of independent children's hospitals had financial losses; many more faced mounting financial pressures. More than 10 percent had negative total margins, more than 20 percent had negative operating margins, and nearly 60 percent had negative patient care margins. Some of the Nation's most prominent children's hospitals were at financial risk. Thanks to CHGME, these hospitals have been able to maintain and strengthen their training programs.

*Pediatric Workforce.*—The important role CHGME plays in the continual development of our Nation's pediatric workforce is not lost on the larger pediatric community, including the American Academy of Pediatrics and Association of Medical School Pediatric Department Chairs. They support CHGME and recognize it is critical not only to the future of the individual hospitals but also to provision of children's health care and advancements in pediatric medicine. This year, the chairs of more than 40 medical school pediatric departments have endorsed full funding for the program, regardless of whether they are affiliated with a CHGME hospital. For example, the pediatric leadership of Iowa has endorsed full funding for CHGME, even though Iowa's own children's hospitals do not receive CHGME funding, because it is so important to the institutions around the country from which Iowa recruits pediatric subspecialists.

#### CONGRESSIONAL RESPONSE

In the absence of movement toward broader GME financing reform, Congress in 1999 authorized the Children's Hospitals' GME discretionary grant program to address the existing inequity in GME financing for the independent children's hospitals. The legislation was reauthorized in 2000 through fiscal year 2005 and provided \$285 million for fiscal year 2001 and such sums as necessary in the years beyond. Congress passed the initial authorization as part of the "Healthcare Research and Quality Act of 1999." It passed the first 5-year reauthorization as part of the "Children's Health Act of 2000." Last year, it passed the second 5-year reauthorization as part of the "Children's Hospital GME Support Reauthorization Act of 2007," which authorized \$330 million for each of the 5 years, through fiscal year 2011.

With this subcommittee's support, Congress appropriated initial funding for CHGME in fiscal year 2000, before the enactment of its authorization. Following en-

actment, Congress moved substantially toward full funding for the program in fiscal year 2001 and completed that goal, providing \$285 million in fiscal year 2002, \$290 million in fiscal year 2003, \$303 million in fiscal year 2004, \$301 million in fiscal year 2005, \$297 million in fiscal year 2006, and \$297 million in fiscal year 2007. (In the fiscal year 2004, 2005, 2006, the funding levels are net of across-the-board cuts in discretionary funding. For example, Congress appropriated \$305 million for fiscal year 2004; the net appropriation, after cut, was \$303 million.)

*Health Resources and Services Administration.*—The CHGME funding is distributed through HRSA to 60 children's hospitals according to a formula based on the number and type of full-time equivalent residents trained, in accordance with Medicare rules, as well as the complexity of care and intensity of teaching the hospitals provide. Consistent with the authorization, HRSA allocates the annual appropriation in monthly payments to eligible hospitals.

#### CHGME'S SUCCESS

The annual CHGME appropriations represent an extraordinary achievement for the future of children's health and the Nation's independent children's teaching hospitals:

- Thanks to CHGME, the Federal Government has made substantial progress in providing more equitable Federal GME support to independent children's hospitals. They now receive about 80 percent of the level of Federal GME support that Medicare provides to other teaching hospitals. It is still not equity, but it is dramatic improvement from the 0.5 percent of 1998.
- Thanks to CHGME, children's hospitals have been able to make a substantial improvement in their contribution to the Nation's pediatric workforce, without having to sacrifice their clinical or research missions. Between 2000 and 2004, without the CHGME hospitals being able to increase the numbers of general pediatric residents they trained, the Nation would have experienced a net decline in the number of new pediatricians. During the same period, CHGME hospitals also accounted for more than 80 percent of the new pediatric subspecialty programs and more than 60 percent of the new pediatric subspecialists trained.
- Thanks to CHGME, children's hospitals have been able to achieve strong, financial positions. According to Moody's Investor Services, before 2000, children's hospitals tended to have negative to break-even financial margins. Since then, they have improved their margins and CHGME is one of the major reasons.

#### FISCAL YEAR 2008 REQUEST

N.A.C.H. respectfully requests that the subcommittee provide equitable GME funding for independent children's hospitals by providing \$330 million in fiscal year 2008, the full authorization level. Such funding is vital for a program that has wage-related and medical teaching costs and experienced 3 years of reductions due to across-the-board cuts before fiscal year 2007.

Adequate, equitable funding for CHGME is an ongoing need. Children's hospitals train new pediatric residents and researchers every year. Children's hospitals have appreciated very much the support they have received, including the attainment of the program's authorized full funding level in fiscal year 2002 and continuation of full funding with an inflation adjustment in fiscal year 2003 and fiscal year 2004. Congress can restore this progress by providing \$330 million in fiscal year 2008.

Continuing equitable CHGME funding is more important than ever in light of continued budget pressures in many States for reductions in Medicaid spending. Because children's hospitals devote a substantial portion of their care to children from low-income families, they are especially affected by Medicaid. Support for a strong investment in GME at children's hospitals is also consistent with the concern Congress has expressed for the health and well-being of children—through education, health and social welfare programs. And it is consistent with the subcommittee's emphasis on the importance of investment in the National Institutes of Health for which we are grateful.

The CHGME funding has been essential to the ability of the independent children's hospitals to sustain their GME programs. At the same time, it has enabled them to do so without sacrificing support for other critically important services that also rely on hospital subsidy, such as many specialty and critical care services, child abuse prevention and treatment services, services to low-income children with inadequate or no coverage, mental health and dental services, and community advocacy, such as immunization and motor vehicle safety campaigns.

In conclusion, CHGME is a success. It is an invaluable investment in children's health. The future of pediatric medicine and children's access to pediatric care de-

depends on it. N.A.C.H. is joined by the American Academy of Pediatrics, American Hospital Association and others in recommending \$330 million for fiscal year 2008.

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PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

On behalf of more than 1,000 Health Center organizations across the country serving more than 16 million patients, the National Association of Community Health Centers (NACHC) is pleased to submit this statement for the record, and to thank the subcommittee for its continued support and investment in the Health Centers program.

ABOUT HEALTH CENTERS

Over more than 40 years, the Health Centers program has grown from a small demonstration project providing desperately needed primary care services in underserved communities to one of the fundamental elements of our Nation's health care safety net. Funding was approved in 1965 for the first two Neighborhood Health Center demonstration projects, one in Boston, Massachusetts, and the other in Mound Bayou, Mississippi.

Today, Health Centers serve as the primary health care safety net for many communities across the country and the Federal grant program enables more low-income and uninsured patients to receive care each year. Health Centers currently serve as the family doctor for one in eight uninsured individuals, and one in every five low-income children. Health Centers are helping thousands of communities address a range of increasing (and costly) health problems, including prenatal and infant health development, chronic illnesses including diabetes and asthma, mental health, substance addiction, domestic violence and HIV/AIDS.

Federal law requires that every Health Center be governed by a community board with a patient majority—a true patient democracy. Health Centers are required to be located in a federally designated Medically Underserved Area (MUA), and must provide a package of comprehensive primary care services to anyone who comes in the door, regardless of their ability to pay. Because of these characteristics, the insurance status of Health Center patients differs dramatically from other primary care providers. As a result, the role of public dollars is substantial. Federal grant dollars, which make up roughly one-quarter of Health Centers' operating revenues, are intended to cover the costs of serving uninsured patients; just over 40 percent of revenues are from reimbursement through Federal insurance programs, principally Medicare and Medicaid. The balance of the revenues are from State and community partnerships, privately insured individuals, and patient's ability to pay.

The Health Centers program is administered by the Bureau of Primary Health Care (BPHC) at the Health Resources and Services Administration (HRSA), within the U.S. Department of Health and Human Services (HHS).

FUNDING BACKGROUND

We greatly appreciate that the subcommittee has approved substantial funding increases for the Health Centers program over the past several years, the result of which has been a broad expansion effort enabling Health Centers to serve many of those that remain underserved in our country. Since 2001, in addition to the overall funding increase, the subcommittee has provided specific increases in funding to stabilize existing centers, as well as to meet the goals of the President's initiative—to significantly impact health care delivery in 1,200 communities through new or expanded Health Centers. With the funding provided in fiscal year 2007, that goal will be met this year.

The Health Centers program has succeeded in expanding access to primary and preventive care services in underserved communities across the country. The Office of Management and Budget rated the Health Centers program as one of the top 10 Federal programs, and the best competitive grant program within all of HHS.

Yet despite this record expansion, hundreds of communities have submitted applications since fiscal year 2002 that received high ratings, but could not be funded due to lack of funds. There is clearly a tremendous need and a tremendous desire to expand Health Center services to new communities. With additional resources, Health Centers stand ready to provide low-cost, highly effective care to millions more uninsured and underserved individuals and families.

In his fiscal year 2008 budget proposal, President Bush requested a total funding level of \$1.988 billion for the Health Centers program. While this represents a slight increase over the President's request in fiscal year 2007, it is essentially the same as the enacted level for fiscal year 2007, as Congress funded the program above the President's request last year. NACHC is requesting an increase of \$200 million for fiscal year 2008, for a total funding level of \$2.188 billion.

In order to truly serve those in need across the country, Health Centers must expand their operations and develop new centers in areas of need. This request represents the next step, an investment in a longer-term plan to provide a health care home in a Health Center to 30 million Americans by 2015, and to eventually bring access to care in a Health Center to every American who needs it within 15 years. We hope to work with the subcommittee to guide this investment around several priorities. First, in the face of rising costs of care and a rising percentage of new patients without insurance coverage, a significant and strategic investment in existing Health Centers is needed to allow them to meet the demand for their services in the communities they serve today. Second, new and expanded Health Centers should be brought to communities with little or no access to care through planning grants and new access point funding targeted to those communities most in need. Lastly, in order to make a comprehensive range of necessary services available at every Health Center, funding should be made available to add mental health, oral health and pharmacy services in high need communities.

In 2005, President Bush called for "a Community Health Center in every poor county" in America. NACHC supports the goal of bringing care to those areas of the country with high poverty and no current access to a Health Center. However, NACHC has expressed the preference that such an expansion address the lack of access in the neediest communities of the country, and that eligibility for new funding not be limited to certain geographic areas such as counties. Further, the President's budget includes proposed legislative language waiving the statutorily designated proportionality requirements for Migrant, Public Housing and Homeless Health Centers in order to implement this second expansion initiative. NACHC strongly opposes this change.

In addition to the expansion efforts, it is critical that Federal funding for Health Centers keep pace with the growing cost of delivering care. NACHC requests that the subcommittee designate \$59 million of any increase in funding to be used to make base grant adjustments for existing centers, allowing an average increase of 3 percent in current Health Center grants. Under the subcommittee's leadership, Congress has provided base grant adjustments for existing centers in 6 out of the 8 previous fiscal years, including \$25 million in fiscal year 2007. A recent study by NACHC found that in the 2 years that these adjustments were not included in the Health Centers appropriation, the number of patient visits per grantee actually decreased.

NACHC appreciates the subcommittee's leadership in stabilizing the Federal Tort Claims Act (FTCA) judgment fund for Health Centers in past years. For fiscal year 2008, the President has requested that \$44,000,000 be appropriated for this purpose. This is \$500,000 below last year's level. NACHC supports maintaining the judgment fund at a total funding level of \$44,500,000.

In 1997, Congress authorized and began funding the HRSA Loan Guarantee Program (LGP) for the construction, renovation, and modernization of Health Centers. Demand for this guarantee program has accelerated significantly in the last several years. NACHC expects that at the current rate of usage, the remaining credit subsidy will be entirely used during calendar year 2008. In response that the success of this program, NACHC is requesting an additional \$5 million be provided until expended for additional loan guarantees. The LGP has proven to be a vital resource for Health Centers across the country—in particular, those on the Gulf Coast—as they seek financing to fund the facilities necessary to accommodate the growth in patient visits resulting from recent expansion efforts.

Finally, in addition to increased funding for the Health Centers program, expanding access to vital preventive and primary health care in underserved communities will also depend on commensurate growth in a number of high-priority programs, including:

- \$150 million for the National Health Service Corps, the largest single source of health professionals for Health Centers. Such an increase will enable the NHSC to place an additional 800 medical professionals;
- \$450 million for Health Professions Training Programs under Title VII/VIII, including \$30 million for Area Health Education Centers (AHECs); and

—\$250 million for Title III of the Ryan White AIDS Program, which provides grants to Health Centers and other primary care providers for outpatient early intervention services.

#### CONCLUSION

America's Health Centers are grateful to the subcommittee for its ongoing efforts to support and stabilize the Health Centers program and to expand health centers' reach into more than 5,000 communities nationwide. As a result of those efforts, more than 16 million people have access to the affordable, effective primary care services that our Nation's Health Centers provide.

We respectfully ask that the subcommittee continue that investment, as the work of caring for our uninsured and medically underserved is far from complete. A recent NACHC study found that some 56 million Americans are still without regular access to primary care. America's Health Centers look forward to meeting that need and rising to the challenge of providing a health care system that works for all Americans. We look forward to working with you over the coming year to move toward that goal.

If you need any additional information or have any questions related to Health Centers or NACHC, please do not hesitate to contact me or John Sawyer, Assistant Director of Federal Affairs, at (202) 331-4603, or via email at jsawyer@nachc.com.

#### PREPARED STATEMENT OF THE NATIONAL CENTER FOR VICTIMS OF CRIME

The National Center for Victims of Crime submits this testimony to urge members of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies to fully fund the Rape Prevention and Education (RPE) Grant program at \$80 million. Rape crisis centers rely on this money to educate their communities about the prevention of sexual abuse and assault. RPE Grant funds provide the foundation for crucial efforts to end sexual violence.

As the leading national resource and advocacy organization for victims of crime, the National Center understands the vital necessity of sexual assault education and outreach programs for victims and their communities. Every day, our Helpline staff speaks to sexual assault victims and connects them with local services. We also work with rape crisis centers and State sexual assault coalitions across the country who have all described to us their desperate struggles to meet their communities' needs. They report that without greater RPE Grant program funding, they cannot continue their education and prevention efforts.

#### PREVALENCE OF RAPE AND SEXUAL ASSAULT

The incidence of sexual assault in this country remains unconscionably high. The latest National Crime Victimization Survey reports that 191,670 people were raped or sexually assaulted in 2005.<sup>1</sup> The crime of sexual violence affects people of all backgrounds and ages—children and adults, males and females. Approximately 1 in 6 women and 1 in 33 men in America have experienced an attempted or completed rape as a child or adult.<sup>2</sup> Young adults and teens are particularly at risk, with people aged 16 to 24 being raped at significantly higher rates than any other age group,<sup>3</sup> and nearly 5 percent of college women being sexually assaulted during any given calendar year.<sup>4</sup>

#### IMPACT ON VICTIMS, FAMILIES, AND COMMUNITIES

Sexual assault exacts a terrible cost on individual victims, their families, and our Nation. The annual cost of sexual assault to victims is approximately \$26 million.<sup>5</sup> Moreover, victims of sexual violence experience higher rates of depression, anxiety disorders, mental illness, addiction, eating disorders, and self-esteem problems than non-victims. Rape survivors are six times more likely to commit suicide than victims of other crimes.<sup>6</sup>

Workplaces and communities are also affected when victims suffer. Rape victims face a loss of economic productivity through unemployment, underemployment, and

<sup>1</sup> Bureau of Justice Statistics, U.S. Dept. of Justice, Criminal Victimization 2005 (Sept. 2006).

<sup>2</sup> Id.

<sup>3</sup> Id.

<sup>4</sup> Fisher, Cullen, & Turner, Nat'l Inst. of Justice & Bureau of Justice Statistics, the Sexual Victimization of College Women (2000).

<sup>5</sup> Bureau of Justice Statistics, U.S. Dept. of Justice, Criminal Victimization 2005 (Sept. 2006).

<sup>6</sup> Arthur H. Green, M.D., Sexual Abuse: Immediate and Long-Term Effects and Intervention, 32 J. AM. ACAD. Child Adolescent Psychiatry. 5, (Sept. 1993).

absence from work. According to the Centers for Disease Control and Prevention (CDC), 21 percent of victims who have been raped by an intimate partner report losing time from work as a result of their victimization.<sup>7</sup>

#### PURPOSES OF THE RAPE PREVENTION AND EDUCATION GRANT PROGRAM

Understanding the far-reaching impact of sexual violence and the importance of prevention, Congress established the CDC's Rape Prevention and Education Program through the Violence Against Women Act of 1994. RPE funding provides formula grants to States and territories to support rape prevention and education programs conducted by rape crisis centers, State sexual assault coalitions, and other public and private nonprofit entities. Funding is used for:

- Educational seminars for professionals, the public, schools, colleges, and universities;
- Hotline operations;
- Education and training programs aimed at preventing sexual violence at colleges and universities; and,
- Education about date rape drugs.

These education and outreach activities are crucial not only to help change public attitudes and behaviors, but also to train allied professionals on issues related to sexual violence so they can better understand victims and make appropriate referrals.

RPE funding also supports the National Sexual Violence Resource Center (NSVRC), a project operated by the Pennsylvania Coalition Against Rape (PCAR). NSVRC provides information, materials, and resources on sexual violence to policy makers, Federal, and State agencies, college campuses, State, territory and tribal sexual assault coalitions, the media, and the public.

#### EDUCATIONAL SEMINARS AND TRAININGS

Rape prevention and education efforts make crucial contributions to ending sexual violence by helping to change attitudes about rape and reduce the isolation of victims. Educational efforts around the country include:

- Kansas: During the 2005 fiscal year, RPE Grant-funded projects provided 2,212 educational sessions to 15,010 students and 267 professionals.
- Mississippi: Over the past 5 years, RPE projects conducted a total of 1,923 community education sessions with 66,422 participants. In addition, the Mississippi Coalition Against Sexual Assault offered a training program for home health workers, nursing home employees, and others in contact with the elderly population to help them identify and respond to signs of abuse and assault.
- Pennsylvania: During the 2006 fiscal year, the PCAR provided 24,213 sexual assault education programs to students and 3,469 prevention education programs to the community.

Many of these educational sessions and trainings, like those conducted in Mississippi, focused on increasing awareness of sexual violence in underserved and at-risk communities. Such outreach also consistently results in an increased number of victims contacting local rape crisis centers for services and support. However, as operation costs increase and funding levels have stagnated, such remarkable efforts cannot expand and grow to reach these vulnerable populations.

#### HOTLINE OPERATIONS

The RPE Grant program also provides crucial support for State and local hotlines, which offer 24-hour crisis intervention, referrals, and information about sexual violence. Importantly, hotline operations allow trained advocates and rape crisis counselors to reach more physically or culturally isolated communities. Recent successes include:

- Massachusetts: Funds from the RPE Grant program permit rape crisis centers across Massachusetts to provide 24-hour hotline services for victims of sexual assault and their families. The program also supports Llamanos, a Spanish-language, toll-free, sexual assault hotline for Latino survivors and their families. Llamanos also provides training for 13 rape crisis centers, five community health organizations, and eight additional community-based agencies serving the Latino population. Together, these hotline services received more than 12,000 calls in the past fiscal year.

<sup>7</sup>Natl Ctr. for Injury Prevention and Control, *Costs of Intimate Partner Violence Against Women in the United States* (Atlanta, Ga., 2003).

—Louisiana: Since Hurricane Katrina struck in 2005, the RPE Grant-funded Louisiana Foundation Against Sexual Assault (LaFASA) has provided hotline services specifically for hurricane victims who were sexually assaulted in the aftermath of the storm. Witnesses, survivors, and their families can call and receive support, counseling, and referral information.

#### PREVENTING SEXUAL VIOLENCE IN SCHOOLS AND ON COLLEGE CAMPUSES

Recognizing that attitudes and beliefs regarding sexual violence are formed early in life, many RPE grantees emphasize education and prevention programs for young people. As youths become aware of the frequency of acquaintance rape, they can and do broaden their efforts to protect themselves, from merely locking doors against strangers to taking precautions with those they know. RPE-funded programs, in collaboration with students and campus personnel, have developed and continue to implement sexual violence prevention programs for schools across the Nation. These programs aim to reduce first-time male perpetration of sexual violence, address norms and beliefs that support or condone sexual violence, and empower bystanders to respond constructively when they recognize abusive relationships. Examples of these programs include:

—*Iowa*.—During the 2006 fiscal year, community prevention specialists conducted 4,599 educational sessions for a total of 71,521 students in grades pre-K through 12. In addition, 244 sexual violence prevention sessions were offered to 14,128 students at Iowa colleges and State universities. After one Iowa event, some female students who had repeatedly endured degrading harassment from fellow classmates came forward to report the incidents to campus authorities, who intervened.

—*California*.—The RPE Grant program funds MyStrength, California's innovative statewide social marketing campaign. This program, which follows a national evidence-based model targeting 14- to 18-year-old males, aims to help prevent first-time perpetration of sexual violence.<sup>8</sup>

—*Indiana*.—The Communities Against Rape Initiative (CARE) is a statewide collaboration supported by the RPE Grant program that helps develop and implement rape prevention curricula for rural, urban, and suburban schools. Since its founding in 1997, CARE has trained more than 1,000 Indiana teachers to use the curricula. Pre- and post-test results from more than 4,600 students show positive changes in students' knowledge and attitudes about rape.<sup>9</sup>

All these remarkable programs and initiatives report that even with such successes, much more could be done to raise awareness about sexual violence in local communities if RPE funding were increased. For instance, the California Coalition Against Sexual Assault (CALCASA) reports that if the national RPE Program were fully funded, the MyStrength campaign could saturate the State with marketing materials, and MyStrength clubs could be sustained in hundreds of high schools throughout California. Such efforts would advance our fight to end sexual violence against men, women, and children.

#### DRUG-FACILITATED SEXUAL VIOLENCE

Drug-facilitated rape is staggeringly pervasive in this country. A recent report from the National Institute on Alcohol Abuse and Alcoholism (NIAAA) shows that more than 70,000 students between the ages of 18 and 24 survive an alcohol or drug-related sexual assault each year.<sup>10</sup> Drugs are used to render victims incapable of providing consent for sexual activity or defending themselves against rape. Because detection and prosecution remain difficult, the best means to prevent these crimes is education. The RPE Grant program funds efforts to raise public awareness of the risk and symptoms associated with Rohypnol, gamma-hydroxybutyrate (GHB), and other common date rape drugs.

#### RAPE PREVENTION AND EDUCATION FUNDING MUST BE INCREASED

Program after program has told the National Center that due to lack of funding they are unable to expand their outreach efforts, staff and volunteers have been taxed to the limit, and they are unable to reprint popular educational materials. Without full funding, these programs cannot make continued progress against sex-

<sup>8</sup>Learn more about the MyStrength campaign at <http://www.mystrength.org> (accessed March 28, 2007).

<sup>9</sup>For more information about the CARE initiative, visit <http://www.four-h.purdue.edu/care/main.html> (accessed March 28, 2007).

<sup>10</sup>Task Force of the Nat'l Advisory Council on Alcohol Abuse and Alcoholism, National Institutes of Health, A Call to Action: Changing the Culture of Drinking at U.S. Colleges (2002).

ual violence. Although the Violence Against Women Act of 2005 (VAWA) reauthorized the Rape Prevention and Education Grant program at \$80 million, funding for the past several years has remained at approximately \$42 million.<sup>11</sup>

When Congress reauthorized the Rape Prevention and Education Grant program as part of VAWA, it recognized the importance of this program in reducing sexual victimization. The National Center calls on Congress to honor its commitment to preventing rape by providing full funding for the Rape Prevention and Education Grant program for the 2008 fiscal year.

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PREPARED STATEMENT OF THE NATIONAL CHILD ABUSE COALITION

The National Child Abuse Coalition, committed to strengthening the Federal response to the protection of children and the prevention child abuse and neglect, urges fiscal year 2008 funding for the Child Abuse Prevention and Treatment Act (CAPTA) programs at the authorized level of \$200 million:

- CAPTA basic State grants at \$84 million;
- CAPTA community-based prevention grants at \$80 million; and
- CAPTA research and demonstration grants at \$36 million.

*Basic State Grants.*—At current funding, child protection agencies are unable to serve close to half the abused and neglected children in their caseloads.

CAPTA funds programs have not kept pace with the needs of communities for supporting families and protecting children. States are hard pressed to treat children or protect them from further harm. In 2004, according to the most recent HHS data, an estimated 3 million reports of possible abuse and neglect were made to States, and almost 900,000 of these reports were substantiated. In 2004, just over 40 percent of the child victims received no services following a substantiated report of maltreatment: suspected abuse reported, report investigated, report substantiated, case closed. Almost 1,500 children died as a result of abuse or neglect. The most endangered are the youngest: more than 80 percent of children who were killed were under age 4.

CAPTA's Basic State Grants help States protect children. The Nation's child welfare system has long been stretched beyond capacity. No State passed the test when measured against the HHS Child and Family Service Reviews to evaluate a State's performance in protecting children. Federal officials repeatedly cited States for certain deficiencies: significant numbers of children suffering abuse or neglect more than once in a 6-month period; caseworkers not visiting children often enough to assess needs; and not providing promised medical and mental health services.

Funding CAPTA State grants at \$84 million would enable State child protective services to expand post-investigative services for child victims, shorten the time to the delivery of services, and increase services to other at-risk families.

*Community-Based Prevention Grants.*—For every Federal dollar spent on foster care and adoption subsidies, we spend less than 13 cents in Federal child welfare funding on preventing and treating child abuse and neglect.

Annual direct costs of child abuse and neglect in the United States total over \$24 billion in hospitalizations, chronic health and mental health care, child welfare services, law enforcement, and courts. Indirect costs from special education, other health and mental health care, crime, and lost productivity, total more than \$94 billion annually.<sup>1</sup> Community services to prevent child abuse are far less costly than the damage inflicted on children from abuse and neglect. A GAO evaluation of child abuse prevention efforts found "total Federal costs of providing prevention programs for low-income populations were nearly offset after 4 years."<sup>2</sup>

CAPTA's Prevention Grants help States to develop community-based prevention services, including parenting education, home visiting services, and respite care. We spend billions of dollars every year on foster care to protect the children who have been the most seriously injured; we can do a much better job at protecting children before the damage is so bad that we have no other choice than to remove them from their homes. Funding CAPTA prevention grants at \$80 million would help communities support proven, cost-effective approaches to preventing child abuse and neglect.

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<sup>11</sup>Passed as part of the Violence Against Women Act 2005 Reauthorization, Public Law 109-162.

<sup>1</sup>Fromm, S. (2001). Total Estimated Cost of Child Abuse and Neglect in the United States. Prevent Child Abuse America.

<sup>2</sup>U.S. General Accounting Office (1992). Child Abuse: Prevention Programs Need Greater Emphasis (GAO/HRD-92-99).

*Discretionary Research and Demonstration Grants.*—Current funding levels short-change community efforts to develop innovative programs to serve children and families and to improve our knowledge about child maltreatment.

We urge Congress to approve the President's proposed increase of \$10 million to support home visitation programs, with funds available to promote an array of research- and evidence-based home visitation models that enable communities to provide the most appropriate services suited to the families needing them.

The U.S. Advisory Board on Child Abuse and Neglect recommended as the highlight of its 1991 report, *Creating Caring Communities*, the establishment of universal voluntary home visitor services. The Centers for Disease Control (CDC) Task Force on Community Preventive Services in its 2003 report evaluating the effectiveness of strategies for preventing child maltreatment "recommends early childhood home visitation for prevention of child abuse and neglect in families at risk for maltreatment, including disadvantaged populations and families with low-birth weight infants."<sup>3</sup>

Research evidence supports the value of a range of early childhood home visitation models using professionals, nurses, paraprofessionals, and trained volunteers from the community in improving parenting and family health and preventing child maltreatment.

For example, results from the randomized trial of the Healthy Families New York program based on the Healthy Families America model using Family Support Workers (specially trained paraprofessionals who live in the target community and share the same language and cultural background as program participants) showed that the program had positive effects in the areas of parenting and child abuse and neglect, birth outcomes, and health care. According to the research team analyzing the Healthy Families program in New York, the results for the subgroup of participants who resemble the clients typically served by the Nurse Family Partnership (NFP) model of home visiting by nurses are similar to those found in randomized trials of NFP.<sup>4</sup>

In another randomized trial, adolescent mothers who received case management services and Parents as Teachers (PAT) home visitors were significantly less likely to be subjected to child abuse investigations than control group mothers who received neither case management nor PAT home visitation.<sup>5</sup> Randomized trials of the Parent-Child Home Program, a home visitation early literacy and parenting program model, show significant ongoing positive effects on parents' interaction with their children, in contrast to control group families examined before and after completion of the program.<sup>6</sup>

In another study of home visiting models funded by CDC, researchers concluded from a literature review of evaluations of home visitation programs that where randomized trials might not always be feasible, non-randomized studies are important to validate research or provide stronger evidence when the randomized trial is compromised. In its review of evaluations of various models, the report found that the evaluated programs reduced child maltreatment by approximately 39 percent, overall.<sup>7</sup>

<sup>3</sup>Hahn, R.A., Bilukha, O.O., Crosby, A., Fullilove, M.T., Liberman, A., Moscicki, E.K., et al. (2003). First reports evaluating the effectiveness of strategies for preventing violence: Early childhood home visitation. Center for Disease Control, Morbidity and Mortality Weekly Report, 52, 109.

<sup>4</sup>DuMont, K., et al. (2006). Healthy Families New York Randomized Trial: Impacts on Parenting After the First Two Years. New York State Office of Children and Families. Working Paper Series.

<sup>5</sup>Wagner, M.M. & Clayton, S.L. (1999). The Parents as Teachers Program: Results from Two Demonstrations. *The Future of Children: Home Visiting: Recent Program Evaluations*, 9(1), 91–115.

<sup>6</sup>Joint Dissemination Review Panel of U.S. Department of Education. (1978). Unanimous Approval of Research Findings, 1967–1978, Mother-Child Home Program of Verbal Interaction Project. Freeport, NY: Verbal Interaction Project.

O'Hara, J.M. & Levenstein, P. (1981). Second Year Progress Report: 9/15/80–9/14/81: Tracing the Parent-Child Network. Final Report, Grant No. NIEG 800042, National Institute of Education, U.S. Department of Education.

Levenstein, P., O'Hara, J.M., & Madden, J. (1983), "The Mother-Child Home Program of the Verbal Interaction Project", in Consortium for Longitudinal Studies, ed., *As the Twig is Bent* Hillsdale, NJ: Lawrence Erlbaum Associates.

Levenstein, P. & O'Hara, J.M., (1993) "The necessary lightness of mother-child play", in K.B. MacDonald, eds., *Parents and Children Playing* Albany, NY: State University of New York Press.

<sup>7</sup>Hahn, R., et al. (2005). Home Visiting Programs to Prevent Child Abuse: Taking Silver and Bronze Along With Gold. U.S. Centers for Disease Control and Prevention. *Child Abuse and Neglect: The International Journal*. Vol. 29, p. 215–218.

Funding research and program innovations at \$36 million, as the President requests, would provide support for a diversity of home visitation models, as well as the field-initiated research, training, technical assistance, and data collection also authorized by CAPTA out of this money.

#### CHILD WELFARE SPENDING: A FAILURE TO INVEST

Our failure to invest in our child protective service system and community-based programs for preventing child maltreatment has created a spending gap of almost \$17 billion in services to intervene on behalf of children. Current available data peg Federal, State, and local dollars for child protective services and preventive services at only about \$3.1 billion of the estimated \$20.2 billion total cost of what we ought to be spending.

According to the Urban Institute, States reported spending \$22 billion on child welfare in 2002, and they could categorize how \$17.4 billion of the funds were used.<sup>8</sup> Of that amount, \$10 billion was spent for out-of-home placements, \$1.7 billion on administration, \$2.6 billion on adoption, and \$3.1 billion (about 18 percent) on all other services, including prevention, family preservation and support services, and child protective services.

Failure to invest in a working child protection system results in a national failure to keep children free from harm. The cost to child protective services in 2002 of investigating the 1.745 million children who were screened in for investigations, plus the expense that would have been incurred if services had been provided to all of the 896,000 substantiated child victims (as well as to the 708,000 children in unsubstantiated reports who also received some services), totals \$7.2 billion. Second, consider the cost of preventive services—\$13 billion if offered to the 3 million child maltreatment victims identified in the HHS National Incidence Study III. That's a total cost of \$18.4 billion. Yet, in 2002, States spent only \$3.1 billion in Federal, State, and local funds on protective and preventive services for children. Our national child welfare policy represents a morally unacceptable failure to invest in this system.

These are conservative cost figures. When adjusted to account for inflation, data indicate that investigations by child protective service agencies cost approximately \$1,011 per case. The cost per case to provide basic in-home services such as home-maker assistance or family counseling is \$3,360.<sup>9</sup> These costs are low to start with. Pay scales in child welfare are generally low and noncompetitive—significantly lower, for example, than salaries for teachers, school counselors, nurses and public-health social workers<sup>10</sup>—which brings these costs in at a low level.

What does the spending gap mean? States report having difficulty in recruiting and retaining child welfare workers,<sup>11</sup> because of issues like low salaries, high caseloads, insufficient training and limited supervision, and the turnover of child welfare workers—estimated to be between 30 and 40 percent annually nationwide.<sup>12</sup> The average caseload for child welfare workers is double the recommended level, and obviously much higher in many jurisdictions.<sup>13</sup> Because our system is weighted toward protecting the most seriously injured children, we wait until it gets so bad that we have to step in. Far less attention in policy or funding is directed at preventing harm to children from ever happening in the first place or providing the appropriate services and treatment needed by families and children victimized by abuse or neglect.

Increasing funding for CAPTA's basic State grants and community-based prevention grants will help to begin to address the current imbalance. It is time to invest additional resources to work in partnership with the States to help families and prevent children from being abused and neglected.

<sup>8</sup> Scarcella, C.A. (2004). *The Cost of Protecting Vulnerable Children IV: How Child Welfare Funding Fared during the Recession*, Washington, DC. Urban Institute.

<sup>9</sup> Courtney, M.E. (1998). "The Costs of Child Protection in the Context of Welfare Reform". *The Future of Children*, Vol. 8, No. 1.

<sup>10</sup> U.S. General Accounting Office (2003). *HHS Could Play a Greater Role in Helping Child Welfare Agencies Recruit and Retain Staff* (GAO-03-357).

<sup>11</sup> U.S. General Accounting Office (1995). *Child Welfare: Complex Needs Strain Capacity to Provide Services* (GAO/HEHS-95-208).

<sup>12</sup> U.S. General Accounting Office (2003). *HHS Could Play a Greater Role in Helping Child Welfare Agencies Recruit and Retain Staff* (GAO-03-357).

<sup>13</sup> Alliance for Children and Families, American Public Human Services Association, Child Welfare League of America (2001). *The child welfare workforce challenge: Results from a preliminary study*. Dallas.

## THE CASE FOR PREVENTION

Our present system of treating abused and neglected children and offering some help to troubled families is overworked and inadequate to the task. Hundreds of thousands of children are currently identified as having been abused, but receive no services to prevent further abuse. We must focus attention on children and families known to the system in order to prevent reoccurrence of abuse, as well as provide services to families earlier, before problems become severe. Putting dollars aside for prevention is sound investing, not luxury spending.

We know that child abuse prevention fights crime, because research has shown us that victims of child abuse are more likely to engage in criminality later in life, and that childhood abuse increases the odds of future delinquency and adult criminality overall by 40 percent.<sup>14</sup> We know that preventing child maltreatment helps to prevent failure in school. Typically abused and neglected children suffer poor prospects for success in school, exhibiting poor initiative, language and other developmental delays, and a disproportionate amount of incompetence and failure.<sup>15</sup> Ensuring that children are ready to learn means ensuring that children are safe at home. We know that preventing child abuse can help to prevent disabling conditions in children. Physical abuse of children can result in brain damage, mental retardation, cerebral palsy, and learning disorders.<sup>16</sup>

Research conducted by CDC in collaboration with Kaiser Permanente shows us that childhood abuse is linked with behaviors later in life which result in the development of chronic diseases that cause death and disability, such as heart disease, cancer, chronic lung and liver diseases, and skeletal fracture, and that the adult victims of child maltreatment are more likely suffer from depression and suicide attempts.<sup>17</sup>

Community-based services to overburdened families are far less costly than the damage inflicted on children that leads to outlays for child protective services, law enforcement, courts, foster care, health care and the treatment of adults recovering from child abuse. A range of services, such as voluntary home-visiting, family support services, parent mutual support programs, parenting education, and respite care contribute to a community's successful strategy to prevent child abuse and neglect.

National Child Abuse Coalition Member Organizations: Alliance for Children and Families, American Academy of Pediatrics, American Bar Association, American Humane Association, American Professional Society on the Abuse of Children, American Psychological Association, Association of University Centers on Disabilities, Boys and Girls Clubs of America, CHILD Inc., Child Welfare League of America, Children's Defense Fund, First Star, General Federation of Women's Clubs, National Alliance of Children's Trust and Prevention Funds, National Association of Children's Hospitals, National Association of Counsel for Children, National Association of Social Workers, Nat'l. Center for Child Traumatic Stress, National Center for State Courts, National CASA Association, National Education Association, National Exchange Club Foundation, National PTA, National Respite Coalition, Parents Anonymous, Prevent Child Abuse America, Voices for America's Children.

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PREPARED STATEMENT OF THE NATIONAL COALITION FOR OSTEOPOROSIS AND RELATED BONE DISEASES

Mr. Chairman and members of the committee: The National Coalition for Osteoporosis and Related Bone Diseases (Bone Coalition) is pleased to have the opportunity to present our views on the fiscal year 2008 budget for the National Institutes of Health (NIH). We are appreciative of your continued support of the NIH. The Federal investment made to date has allowed for new research opportunities to be pursued that hold the potential to prevent and one day possibly cure diseases such as osteoporosis, osteogenesis imperfecta and Paget's disease of bone.

The leaders of the Coalition are the National Osteoporosis Foundation, the American Society for Bone and Mineral Research, the Osteogenesis Imperfecta Foundation and the Paget Foundation for Paget's Disease of Bone and Related Disorders.

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<sup>14</sup>C.S. Widom (1992). *The Cycle of Violence*. Washington, DC: National Institute of Justice.

<sup>15</sup>S.R. Morgan (1976). *The Battered Child in the Classroom*. Journal of Pediatric Psychology.

<sup>16</sup>H.P. Martin & M.A. Rodeheffer (1980). *The Psychological Impact of Abuse in Children*. In: G.J. Williams. *Traumatic Abuse and Neglect of Children at Home*. Baltimore, MD: Johns Hopkins University Press.

<sup>17</sup>V.J. Felitti, R.F. Anda, et al. (1998). *Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults. The Adverse Childhood Experiences (ACE) Study*. American Journal of Preventive Medicine.

Throughout our existence, the Coalition has remained committed to reducing the impact of bone disease through expanded biomedical, clinical, epidemiological and behavioral research.

Bone health is integral to the overall health and well being of the Nation's population. The bony skeleton is a remarkable organ that not only serves a structural function, providing mobility, support, and protection for the soft tissues, but also functions as a reservoir or storehouse for essential minerals and growth factors. It may even potentially act as an endocrine organ.

The 2004 Surgeon General's Report on Bone Health and Osteoporosis calls bone health an "often overlooked aspect of physical health" and further States that "[a] healthy skeletal system with strong bones is essential to overall health and quality of life. Yet, today, far too many Americans suffer from bone diseases and fractures."

Bone diseases such as osteoporosis, osteogenesis imperfecta, and Paget's disease of bone remain a major public health problem in this country and the financial, physical and psychosocial consequences of bone diseases significantly diminish quality of life and burden society.

*Osteoporosis.*—Is a disease characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and an increased susceptibility to fractures, particularly of the hip, spine, and wrist. This is due to several factors such as the aging of our population, increased use of steroids and other drugs that have deleterious effects on bone, and increased immobilized patients and nursing home populations. Over 10 million Americans have osteoporosis, the majority of whom (80 percent) are women; 34 million more have low bone mass and are at increased risk for the disease. The estimated national direct expenditures for osteoporosis and related fractures total \$18 billion each year in 2002 dollars.

*Paget's Disease of Bone.*—The second most prevalent bone disease after osteoporosis—is a chronic skeletal disorder that may result in enlarged or deformed bones in one or more regions of the skeleton. Excessive bone breakdown and formation can result in bone that is dense, but fragile. Complications may include arthritis, fractures, bowing of limbs, neurological complications, and hearing loss if the disease affects the skull. Prevalence in the population ranges from 1.5 percent to 8 percent depending on the person's age and geographical location. Paget's disease primarily affects people over 50.

*Osteogenesis Imperfecta.*—Causes brittle bones that break easily due to a problem with collagen production. For example, a cough or sneeze can break a rib, rolling over can break a leg. Besides fragile bones, people with OI may have hearing loss, brittle teeth, short stature, skeletal deformities, and respiratory difficulties. OI affects between 20,000 to 50,000 Americans. In severe cases fractures occur before and during birth. In some cases, an affected child can suffer repeated fractures before a diagnosis can be made. Undiagnosed OI may result in accusations of child abuse.

*Cancer Metastasis to Bone.*—A frequent complication of cancer is its spread to bone (bone metastasis) that occurs in up to 80 percent of patients with myeloma and 70 percent of patients with either breast or prostate cancer—causing severe bone pain and pathologic fractures. Only 20 percent of breast cancer patients and 5 percent of lung cancer patients survive more than 5 years after discovery of bone metastasis.

*Musculoskeletal Trauma and Skeletal Pain.*—Of the 60 million Americans injured annually, more than one-half incur injuries to the musculoskeletal system. In the United States, back pain is a major reason listed for lost time from work and sports injuries are increasing in "weekend warriors" of both sexes. In our military, bone trauma is now accounting for over 50 percent of all combat injuries.

#### HOW HAS BONE RESEARCH HELPED PEOPLE?

NIH-supported research in bone health has led to important discoveries and has generated new treatments and pharmaceutical products.

- Research has taught us that those with low bone mass are at risk for osteoporosis. These individuals can then address their risk with exercise, diet, other behavioral and lifestyle changes, and medication.
- Research has decreased fracture risk and extended the lifespan to normal for people with OI.
- Research has identified drugs which improve the quality of life of people whose cancer has metastasized to bone.
- Research has led us to develop simple, non-invasive and accurate tests that can determine bone mass and help predict fracture risk.
- Research has identified and demonstrated a variety of drugs that can reduce bone loss and fractures, and even build new bone. Thirty years ago, there was no treatment for osteoporosis.

- Research has helped us to understand the need for weight-bearing exercise to build and maintain bone in order to reduce fracture risk. Falling can be reduced by strength-building exercise that increases balance and flexibility.
- Research has led to the discovery of a recessive form of osteogenesis imperfecta, providing new possibilities for prevention, treatment and a cure. But much remains to be done.

#### FUTURE OPPORTUNITIES FOR BONE RESEARCH

*Osteoporosis.*—Research has the potential to add important new information to our understanding of osteoporosis.

- Therapies such as calcium supplementation and physical activity need to be explored to help chronically ill children reach and maintain peak bone mass.
- Data on the beneficial and/or adverse effects of bone therapies such as bisphosphonates in children as well as adults with many chronic diseases such as diabetes, inflammatory arthritis and osteogenesis imperfecta are almost nonexistent and are sorely needed.
- The pathophysiology of bone loss in diverse populations needs to be studied in order to develop targeted therapies to improve bone density and bone quality.
- Racial differences in bone and the origin of racial differences in fracture patterns need to be identified to understand important determinants of fracture and their underlying biology.
- Patients at risk for fracture who do not meet current criteria for osteoporosis need to be identified. In addition, the effects of current and developing osteoporosis treatments on these patients need to be studied.
- Research into gene targeting which could cure osteogenesis imperfecta is a few short years away from human trials. Continued research into drug therapies is needed to improve bone quality, allowing people with osteogenesis imperfecta to live independently.

*Congenital and Genetic Disease of Bone.*—Thousands of children and adolescents nationwide suffer from musculoskeletal disorders and malformations, many of which have devastating effects on mortality and disability. Diseases such as osteogenesis imperfecta, fibrous dysplasia, osteopetrosis, and Paget's disease are caused by poorly understood genetic mutations. In Paget's disease, underlying genetic defects can also be exacerbated by environmental factors. Increased research on the role of the environmental and genetic factors in the development of Paget's disease could lead to the identification of new therapeutic targets for the disease. The science of genetics has led to tremendous advances in our understanding of numerous systems that affect bone health, but little of this technology is being applied to bone research. Knowledge of complex gene pathways must be used to deepen our understanding of bone biology to gain better insight into the causes of these debilitating diseases. Research is needed that:

- Focuses on mechanisms of preventing fractures and improving bone quality and correcting malformations, on innovations in surgical and non-surgical approaches to treatment, on physical factors that affect growth, and on genetic defects that cause bone disease.
- Expands research on skeletal stem cell biology and the genetics and pathophysiology of rare disorders such as fibrous dysplasia, melioretosis, X-linked hypophosphatemic rickets and fibrodysplasia ossificans progressiva.

*Cancer Metastasis to Bone.*—Immune response plays a role in cancer metastasis. Osteoimmunology—the study of the relationships between the immune system and bone homeostasis—is an emerging area of research and may help scientists prevent and treat the spread of cancer to bone. Research is needed to:

- Determine mechanisms and to identify, block and treat cancer metastasis to bone.
- Expand research on osteosarcoma to improve survival and quality of life and to prevent metastatic osteosarcoma in children and teenagers who develop this cancer.
- Expand research on tumor dormancy as it relates to bone metastasis.

*Musculoskeletal Trauma and Skeletal Pain.*—Research is needed to better understand the epidemiology of back pain, improve on existing diagnostic techniques for back pain, as well as to develop new ones. Furthermore, expanded research is needed to improve diagnostic and therapeutic approaches to significantly lower the impact of musculoskeletal traumas, and on research on accelerated fracture healing, the use of biochemical or physical bone stimulation, the role of hematopoietic niches to preserve bone stem cells, the use of mesenchymal bone stem cells, and biomaterials and biologicals in bone repair and regeneration, and research into repair of nonunion fractures in osteogenesis imperfecta.

*Bone Strength.*—Research is also needed in the area of bone strength. Although bone mineral density has been a useful predictor of susceptibility to fracture, other properties of the skeleton contribute to bone strength, such as geometry and composition. At this time, little is understood as to how these properties influence bone strength. However, research clearly indicates that exercise that causes mechanotransduction plays a key role in the maintenance of bone; and loss of bone due to immobilization as occurs in patients in hospitals and nursing homes may be preventable with therapies that mimic mechanotransduction. Bone strength is also influenced by the amount of mineral, however, how the bone becomes mineralized is not well understood. Understanding this process should assist in prevention of pathologic mineralization as occurs in hardening of the arteries that causes heart attacks. Research, including research on bone structure and periosteal biology, is needed which will achieve identification of the parameters that influence bone strength and lead to better prediction for prevention and treatment of bone diseases such as osteoporosis, osteogenesis imperfecta, bone loss due to kidney disease, and hardening of the arteries.

To move this research forward, Congress must provide sufficient funding to the National Institutes of Health to sustain the robust research atmosphere in which to address the challenges in the bone field. Research must continue to be accelerated in order to improve the health of the Nation.

#### RECOMMENDATION

The National Coalition for Osteoporosis and Related Bone Diseases supports:

- a 6.7 percent increase in funding for the National Institutes of Health as recommended by the Ad Hoc Group for Medical Research, the Campaign for Medical Research, the Federation of American Societies for Experimental Biology, the National Health Council, and Research!America.
- a 6.7 percent increase for the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the lead institute for bone research.
- increased funding for NIA, NIDCR, NIDDK, NCI and NICHD, other Institutes that also fund bone-related research, as well as additional support for bone programs at NIBIB and NCAM.

Thank you for the opportunity to submit our statement regarding the fiscal year 2008 budget for the National Institutes of Health.

#### PREPARED STATEMENT OF THE NATIONAL CONSUMER LAW CENTER ON BEHALF OF OUR LOW-INCOME CLIENTS<sup>1</sup>

The Federal Low Income Home Energy Assistance Program (LIHEAP)<sup>2</sup> is the cornerstone of government efforts to help needy seniors and families avoid hypothermia in the winter and heat stress (even death) in the summer. We are in a sustained period of much higher household energy prices and expenditures and the demand for this program is growing as increases in energy prices far outstrip the ability of low income households to pay. In light of the crucial safety net function of this program in protecting the health and well-being of low-income seniors, the disabled and families with very young children, we respectfully request that LIHEAP be fully funded at its authorized level of \$5.1 billion for fiscal year 2008 and that advance funding of \$5.1 billion be provided for the program in fiscal year 2009.

#### COST OF HOME ENERGY REMAINS AT RECORD HIGH LEVELS

Residential heating expenditures remain at record high levels. According to the Department of Energy's Energy Information Administration's March 2007 Short-Term Energy Outlook, this winter's average residential heating expenditures are projected to be 53 percent higher for heating oil, 29.6 percent higher for natural gas, 39.4 percent higher for propane, and 18.6 percent higher for electricity than the averaged expenditures for 2000–2005. This U.S. Department of Energy short-term forecast of residential heating expenditures shows that, on average, residential bills are still among the highest on record. The cost of electricity, used for both heating and cooling, has been increasing rapidly due, in part, to increases in the price of natural gas used to generate electricity in many power plants and the lifting of price caps in States that restructured their electric markets.

In a brief span of time, energy bills have walloped low-income households. In 2008, LIHEAP eligible households are predicted to spend, depending on the type of

<sup>1</sup>Mass Union of Public Housing Tenants and Pennsylvania Utility Law Project.

<sup>2</sup>42 U.S.C. §§ 8621 et seq.

heating fuel used, 63 percent more on their total residential energy bills than in 2001 if they used heating oil, 36 percent more if they used natural gas, 47 percent more if they used propane and 34 percent more if they use electricity. The effect of these continually rising prices on low-income households is devastating.

STATES' DATA ON ELECTRIC AND NATURAL GAS DISCONNECTIONS AND ARREARAGES  
SHOW THAT MORE HOUSEHOLDS ARE FALLING BEHIND

Not surprisingly, the steady and dramatic rise in residential energy costs has resulted in increases in electric and natural gas arrearages and disconnections. For example, utility service disconnections in Rhode Island increased by over 92 percent between the years 2000 and 2006. Similarly, the gap between service disconnections and reconnections increased, suggesting increased durations of service loss and greater numbers of households that do not regain access to service under their own accounts.<sup>3</sup>

Although there are winter utility shut-off moratoria in place for many States, not every home is protected against energy shut-offs in the middle of winter. As we approach the lifting of winter shut-off moratoria, we expect to see a wave of disconnections as households are unable to afford the cost of the energy bills.

*Iowa.*—Despite milder winter temperatures this winter, the continued high cost of natural gas has set back a record number of low-income households in Iowa. In February 2007, the number of low-income households with past due energy accounts was the second highest on record for this time of year since these data have been tracked. As an indication of the effect of long term effect of rising home energy prices, the total number of LIHEAP households in arrears in February 2007 was 80 percent higher than 5 years ago at this point in time and 151 percent higher than in February 1999. The total amount of arrearages of LIHEAP households has also grown sharply due to the increase in prices. By February 2007, the total amount of LIHEAP household arrears had increased 42 percent from the same period 5 years ago and 163 percent compared to arrears in February 1999. The total number of LIHEAP households served in fiscal year 2007 is expected to remain at the record high level of fiscal year 2006, yet the program received \$16 million less under the fiscal year 2007 appropriations. In order to serve the increased demand for LIHEAP this heating season the program reduced benefits by 30 percent and redirected LIHEAP funds normally dedicated to the summer pre-purchase of deliverable fuels (a program component that maximizes purchasing power).<sup>4</sup>

*Ohio.*—In Ohio, the number of households entering into the State's low-income energy affordability program, the Percentage of Income Payment Program (PIPP), increased 13 percent from January 2006 to January 2007. The increase is an even more dramatic 64 percent between January 2002 and January 2007. The total dollar amount owed (arrearage) by low-income PIPP customers increased 8 percent from January 2006 to January 2007 and 62 percent when comparing PIPP customer arrears from January 2002 to January 2007. The National Energy Assistance Directors Association estimates that the number of households applying for energy assistance in fiscal year 2007 is likely to remain at fiscal year 2006 levels, for Ohio that would mean an estimated 30 percent more households when compared to Ohio households that received heating assistance in fiscal year 2002.<sup>5</sup>

*Pennsylvania.*—Utilities in Pennsylvania that are regulated by the Pennsylvania Public Utility Commission (PA PUC) have established universal service programs that assist utility customers in paying bills and reducing energy usage. Even with these programs, electric and natural gas utility customers find it difficult to keep pace with their energy burdens. The PA PUC estimates that more than 19,700 households entered the current heating season without heat-related utility service—this number includes about 3,700 households who are heating with potentially unsafe heating sources such as kerosene or electric space heaters and kitchen ovens. In mid-December 2006 an additional 9,000 residences where electric service was previously terminated were vacant and over 7,500 residences where natural gas

<sup>3</sup> Calculated from data provided by the Rhode Island Public Utilities Commission.

<sup>4</sup> Iowa Bureau of Energy Assistance, National Energy Assistance Directors' Association's "LIHEAP Survey Results—Status of fiscal year 2007 Program Funding (March 7, 2007) and the National Energy Assistance Directors' Association, "The Low Income Home Energy Assistance Program: Providing Heating and Cooling Assistance to Low-Income Families During a Period of High Energy Prices (February 9, 2007). NEADA documents are available at [www.neada.org](http://www.neada.org).

<sup>5</sup> Public Utilities Commission of Ohio, National Energy Assistance Directors' Association's "LIHEAP Survey Results—Status of Fiscal Year 2007 Program Funding (March 7, 2007), the National Energy Assistance Directors, "Est. Total Households Receiving LIHEAP Heating Assistance by State—Projected Applications for Fiscal Year 2006 (2/13/06) and "Estimated Total Households Receiving LIHEAP Heating Assistance by State Actuals in 2002, 2003; Projected in 2004." NEADA documents are available at [www.neada.org](http://www.neada.org).

service was terminated were vacant. In 2006, the number of terminations increased 32 percent compared with terminations in 2004. As of February 2007, 18.9 percent of residential electric customers and 16.3 percent of natural gas customers were overdue on their energy bills. The National Energy Assistance Directors Association estimates that the number of households applying for energy assistance in fiscal year 2007 is likely to remain at fiscal year 2006 levels, for Pennsylvania that would mean an estimated increase of over 354,065 LIHEAP households from in fiscal year 2005 levels. However, in fiscal year 2007 Pennsylvania is experiencing a 34 percent reduction in LIHEAP funding compared to levels in fiscal year 2006. This reduction in funding has resulted in a 32 percent cut to the average LIHEAP crisis benefit from \$422 in fiscal year 2006 to \$285 in fiscal year 2007 (year to date).<sup>6</sup>

LIHEAP IS A CRITICAL SAFETY NET PROGRAM FOR THE ELDERLY, THE DISABLED AND HOUSEHOLDS WITH YOUNG CHILDREN

In fiscal year 2006, 5.7 million households received LIHEAP heating assistance, the highest number of households served in 13 years. Preliminary estimates by the National Energy Assistance Directors' Association are that fiscal year 2007 participation rates will remain near the same record levels as in fiscal year 2006.<sup>7</sup> Yet, energy prices have been on a continued upward climb. These two trends cut into the ability of the LIHEAP program to help protect our most vulnerable citizens from extreme weather conditions that cause illness, physical harm and even death.

Recent national studies have documented the dire choices low-income households are faced with when energy bills are unaffordable. Because adequate heating and cooling are tied to the habitability of the home, low-income families will go to great lengths to pay their energy bills. Low-income households faced with unaffordable energy bills cut back on necessities such as food, medicine and medical care.<sup>8</sup> The U.S. Department of Agriculture recently released a study that shows the connection between low-income households, especially those with elderly persons, experiencing very low food security and heating and cooling seasons when energy bills are high.<sup>9</sup> A pediatric study in Boston documented an increase in the number of extremely low weight children, age 6 to 24 months, in the 3 months following the coldest months, when compared to the rest of the year.<sup>10</sup> Clearly, families are going without food during the winter to pay their heating bills, and their children fail to thrive and grow.

When people are unable to afford paying their home energy bills, dangerous and even fatal results occur. Families resort to using unsafe heating sources, such as space heaters, ovens and burners, all of which are fire hazards.<sup>11</sup> In the summer, the inability to afford cooling bills can result in heat-related deaths and illness. The loss of essential utility services can be devastating, especially for poor families that can find themselves facing hypothermia in the winter, hyperthermia in the summer, eviction, property damage from frozen pipes, the use of dangerous alternative sources of heat.

<sup>6</sup>Pennsylvania Public Utility Commission Bureau of Consumer Services, National Energy Assistance Directors' Association's "LIHEAP Survey Results—Status of Fiscal Year 2007 Program Funding (March 7, 2007) and National Energy Assistance Directors' Association, "The Low Income Home Energy Assistance Program: Providing Heating and Cooling Assistance to Low-Income Families During a Period of High Energy Prices (February 9, 2007). NEADA documents are available at <http://www.neada.org>.

<sup>7</sup>National Energy Assistance Directors' Association, Talking Points in Support of Additional Federal and State Grant Funding for Energy Assistance (Jan. 19, 2007) available at [www.NEADA.org](http://www.NEADA.org).

<sup>8</sup>See e.g., National Energy Assistance Directors' Association, 2005 National Energy Assistance Survey, Tables in section IV,G (September 2005) (To pay their energy bills, 20 percent of LIHEAP recipients went without food, 35 percent went without medical or dental care, 32 percent did not fill or took less than the full dose of a prescribed medicine). Available at [http://www.neada.org/comm/surveys/NEADA\\_2005\\_National\\_Energy\\_Assistance\\_Survey.pdf](http://www.neada.org/comm/surveys/NEADA_2005_National_Energy_Assistance_Survey.pdf).

<sup>9</sup>Mark Nord and Linda S. Kantor, Seasonal Variation in Food Insecurity Is Associated with Heating and Cooling Costs Among Low-Income Elderly Americans, *The Journal of Nutrition*, 136 (Nov. 2006) 2939–2944.

<sup>10</sup>Deborah A. Frank, MD et al., Heat or Eat: The Low Income Home Energy Assistance Program and Nutritional and Health Risks Among Children Less Than 3 years of Age, *AAP Pediatrics* v.118, no.5 (Nov. 2006) e1293-e1302. See also, Child Health Impact Working Group, Unhealthy Consequences: Energy Costs and Child Health: A Child Health Impact Assessment Of Energy Costs And The Low Income Home Energy Assistance Program (Boston: Nov. 2006).

<sup>11</sup>John R. Hall, Jr., Home Heating Fire Patterns and Trends (In 2003 there were over 53,000 heating-equipment related home fires resulting in 260 deaths (73 percent of the deaths involved portable space heaters) and 1,260 injuries and \$494 million in property damage), National Fire Protection Association (Nov. 2006).

LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable low-income seniors, the disabled and families with young children. LIHEAP must be fully funded at its authorized level of \$5.1 billion in fiscal year 2008 in light of the steady increase in home energy costs and the increased need for assistance to protect the health and safety of low income families by making their energy bills more affordable. In addition, fiscal year 2009 advance funding would facilitate the efficient administration of the State LIHEAP programs. Advanced funding provided certainty of funding levels to States to set income guidelines and benefit levels before the start of the heating season. States can also plan the components of their program year (e.g., amounts set aside for heating, cooling and emergency assistance, weatherization, self-sufficiency and leveraging activities).

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PREPARED STATEMENT OF THE NATIONAL COUNCIL OF SOCIAL SECURITY  
MANAGEMENT ASSOCIATIONS

Chairman Harkin, Senator Specter and members of the subcommittee, my name is Richard Warsinsky and I represent the National Council of Social Security Management Associations (NCSSMA). I have been the manager of the Social Security office in Downtown Cleveland, Ohio for nearly 12 years and have worked for the Social Security Administration for 31 years. On behalf of our membership, I am pleased to have the opportunity to submit this written testimony to the subcommittee.

The NCSSMA is a membership organization of nearly 3,400 Social Security Administration (SSA) managers and supervisors who provide leadership in over 1,300 Field Offices and Teleservice Centers throughout the country. We are the front-line service providers for SSA in communities all over the Nation. We are also the Federal employees with whom many of your staff members work to resolve problems and issues for your constituents who receive Social Security retirement benefits, survivors or disability benefits, or Supplemental Security Income. From the time our organization was founded over 36 years ago, the NCSSMA has been a strong advocate of efficient and prompt locally delivered services nationwide to meet the variety of needs of beneficiaries, claimants, and the general public. We consider our top priority to be a strong and stable Social Security Administration, one that delivers quality and prompt community based service to the people we serve—your constituents.

IMPACT OF SSA'S APPROPRIATED FUNDING LEVEL ON SSA FIELD OFFICES & TELESERVICE  
CENTERS

For fiscal year 2008, the President has proposed an increase for SSA of approximately \$304 million over the final level of funding for fiscal year 2007. And yet, staffing levels in offices across the country are being cut. In fact, SSA will lose about 4,000 positions from the beginning of fiscal year 2006 to fiscal year 2008. The most significant staffing losses in SSA have occurred in the agency's Field Offices. Field Offices have lost about 2,300 positions in the past 18 months and about 1,200 positions since September 2006. The vast majority of these losses have been in the most critical positions in the Field: Claims Representatives and Service Representatives. All of this comes after 5 years of reductions to the President's Budget Requests, which total \$720.0 million, and about 8,000 work years. It is interesting to note that while total Executive Branch Employment is expected to increase 2.1 percent from fiscal year 2006 to fiscal year 2008, SSA's employment is expected to decrease by 6.2 percent.

In 2007, an average of 858,000 people are visiting Social Security Administration Field Offices every week. At the same time, Field Offices are also being overwhelmed by business-related telephone calls. SSA Field Offices are receiving approximately 68 million business related phone calls a year. This is in addition to the 44 million phone calls handled by live agents that are received by SSA's 1-800 number on an annual basis. The fact that the public can't get through to SSA on the telephone is creating an overwhelming amount of walk-in traffic in many Field Offices. Waiting times in many Field Offices are running 2 to 3 hours long. Some visitors are even experiencing wait times of over 4 hours.

SSA is also facing a retirement wave as many of its employees were hired around the time SSA took over the Supplemental Security Income (SSI) program in 1974. It is important for the agency to be able to replace this wealth of experience. It can take up to 4 years before newly hired Claims Representatives become fully proficient in the very complicated programs SSA administers.

The impact of inadequate resources in recent years is apparent in the severe cut-backs in processing Continuing Disability Review cases and SSI Redeterminations. For every \$1 spent on a Continuing Disability Review, \$10 is saved. SSA currently has a backlog of 1.3 million Continuing Disability Review cases. The agency also saves \$7 for every \$1 spent on an SSI redetermination. SSA was unable to process over 2.0 million of these cases in the past few years due to the lack of resources.

In recent months I have received hundreds of messages from SSA Field Office management describing how the stress in their offices is incredible. Health problems are growing. It truly is a dire situation. I would like to share with you part of a communication I received from a member of Field Office management:

"We have lost five employees recently. Two had strokes in the office in the last month and it may have been due to all the stress. Another employee is retiring next month. We are simply being hammered with work. The number of people visiting our office is well beyond our capacity to handle them. About 30.0 percent of our visitors live outside our service area. We don't receive staff for these extra visitors and the loss of staff has made it an impossible situation.

"We really have a very dedicated and wonderful staff. But so many are about to have a breakdown. We are just desperate to get help."

Even if SSA receives the funding increase recommended by the President for fiscal year 2008, staffing will be cut because SSA's expenditures continue to increase in several areas. Salaries and benefit costs, including those for the Disability Determination Services, rent, and security costs, are totaling more than the annual increases in appropriated funds. And for fiscal year 2007, SSA's final level of funding was just enough to avoid an agency-wide furlough. Although a furlough was avoided, the agency will be faced with limited hiring for the entire year after only being able to replace one out of three staffing losses last year.

As a result, the fiscal year 2008 President's budget request will provide fewer, not additional, resources for SSA. Therefore, we are in strong support of the additional funding recommended in the Fiscal Year 2008 Senate Budget Resolution. These additional funds would be a major step in restoring SSA's service to appropriate levels.

#### SURVEY OF OUR MEMBERS

Our association just completed a survey of our members. Over 2,000 responded. The gravity of the losses in the Field Offices can be seen in an answer to one question. The question was: "Do you have enough staff to keep workloads current?" Only 3.2 percent answered "yes" to this question.

The losses in staff in Field Offices are having a significant impact on our ability to provide good service. In answer to the question: "What percent of the time are Field Offices able to provide prompt telephone service?" nearly 63 percent said they can only do this 50 percent or less of the time. Nearly a third said they can provide prompt telephone service less than 25 percent of the time. The impact of these staffing losses can also be seen in the increased waiting times for the public. In answer to the question as to whether waiting times had increased in the past 2 years, 80 percent said "yes" and nearly a third said the waiting times were significantly longer.

#### DISABILITY BACKLOGS

It is also important to note that receiving prompt service is not the case for hundreds of thousands of claimants that have filed for Social Security and SSI Disability benefits. There are currently over three quarter of a million hearings pending. And at the moment, it is taking 510 days, on average, for a hearings decision. Nearly 300,000 hearings have been pending over a year. SSA estimates that the hearings backlog could grow to 1 million cases by 2010 if additional resources are not provided for SSA.

SSA also has a total of about 1.4 million disability cases pending at the initial claims, reconsideration, and hearings levels. We estimate about 125,000 of these cases belong to veterans and about half of these are pending at the hearings level.

Every day SSA Field Offices and Teleservice Centers throughout the country are being contacted by people regarding the status of their hearings as I am sure most congressional offices are. Many of these people are desperate and have insufficient funds to live on and the delays only add to their sense of hopelessness.

At the beginning of this decade there were only about 311,000 hearings pending, and the average time for processing was just 274 days. So the pending cases have grown 130.0 percent in 6 years, and the average time to process a case has increased by 234 days. These long waits occur after most claimants have passed the first two stages of their claim, having received an initial decision and a reconsideration. By this point, over 200 days on average have already passed by.

## THE IMPACT OF THE BABY BOOMERS RETIRING

Next year, in 2008, the first of 78 million baby boomers will be eligible for Social Security retirement. So there will be a steady rise in retirement claims with SSA—along with an increasing number of contacts by these retirees with SSA once they start receiving benefits.

At the end of 2006, there were 40.3 million people receiving retirement and survivor benefits. This figure is expected to rise by about 1 million a year over the next 10 years and accelerate after this. SSA took about 3.3 million retirement and survivor claims last year. So we are looking at a significant increase in work for SSA offices.

## THE COMMISSIONER'S BUDGET

Because SSA is an independent agency, the Commissioner is required by law to prepare an annual budget request for SSA, which is submitted by the President to Congress without revision, together with the President's budget request for SSA. This budget request reflects what the Commissioner has evaluated as the level of funding necessary to meet the agency's service delivery improvements and fiscal stewardship responsibilities through 2012. The Commissioner's budget request also factors in that SSA has received less than the President's recommended level of funding in recent years, thus leading to the need for additional resources in the future to meet the full service delivery plan. The budget amount submitted by the Commissioner of Social Security for fiscal year 2008 is \$10.44 billion. This \$10.44 billion is \$843 million more than what the President requested. The difference between these proposed funding levels is significant. Of more significance is the difference between the final funding levels approved by Congress for SSA in comparison to the budget requests submitted in recent years by the Commissioner. Inadequate levels of resources have contributed to the growing inability of SSA to provide adequate levels of service.

## SOCIAL SECURITY TRUST FUND

The Social Security Trust Fund currently totals approximately \$2.0 trillion. The Social Security Trust Fund is intended to pay benefits to future beneficiaries and finance the operations of the Social Security Administration. The additional funding for SSA proposed in the fiscal year 2008 Senate Budget Resolution represents about 1/65th of 1 percent of \$2 trillion. Don't the workers who have paid into this trust fund with their taxes deserve to receive due consideration and the very benefits they have paid for in a timely manner?

The Social Security Trust Fund contains the necessary resources to make up the difference between the level requested by SSA's Commissioner and the President. Yet, because of the levels of service that SSA and its various components that process disability claims are currently able to provide, many of these taxpayers must wait so long for service that they die before a decision is made on their case. They never receive the benefits that they have paid for. This also applies to receiving good service in Social Security Administration Field Offices—it currently is not at the level it ought to be and people are not receiving what they have paid for and what they deserve.

## CONCLUSION

The NCSSMA believes that the American public wants and deserves to receive good and timely service for the tax dollars they have paid to receive Social Security. We urge approval of at least the amount included in the Fiscal Year 2008 Senate Budget Resolution, and encourage you to consider providing the level of funding requested by the Commissioner of Social Security. This additional funding would certainly begin the necessary process to restore the levels of service that the public deserves from SSA.

On behalf of the members of the NCSSMA, I thank you again for the opportunity to submit this written testimony to the subcommittee. Our members are not only dedicated SSA employees, but they are also personally committed to the mission of the agency and to providing the best service possible to the American public. We respectfully ask that you consider our comments and would appreciate any assistance you can provide in ensuring that the American public receives the necessary service that they deserve from the Social Security Administration.

## PREPARED STATEMENT OF THE NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

Thank you for the opportunity to submit testimony to this subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the president and CEO of the National Federation of Community Broadcasters, I speak on behalf of 250 community radio stations and related organizations across the country. Nearly half our members are rural stations and half are controlled by people of color. In addition, our members include many of the new Low Power FM stations that are putting new local voices on the airwaves. NFCB is the sole national organization representing this group of stations which provide service in the smallest communities of this country as well as the largest metropolitan areas.

In summary, the points we wish to make to this subcommittee are that NFCB:

- Requests \$440 million in funding for CPB for fiscal year 2010;
- Requests \$40 million in fiscal year 2008 for conversion of public radio and television to digital broadcasting;
- Requests \$27 million in fiscal year 2008 for replacement of the radio interconnection system;
- Requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fundraising by public broadcasters;
- Reject the administration's proposal to rescind \$107.35 million of already-appropriated 2008 CPB funds;
- Supports CPB activities in facilitating programming and services to Native American, African American and Latino radio stations;
- Supports CPB's efforts to help public radio stations utilize new distribution technologies and requests that the subcommittee ensure that these technologies are available to all public radio services and not just the ones with the greatest resources.

Community Radio fully supports \$440 million in Federal funding for the Corporation for Public Broadcasting in fiscal year 2010. Federal support distributed through CPB is an essential resource for rural stations and for those stations serving communities of color. These stations provide critical, life-saving information to their listeners and are often in communities with very small populations and limited economic bases, thus the community is unable to financially support the station without Federal funds.

In larger towns and cities, sustaining grants from CPB enable Community Radio stations to provide a reliable source of noncommercial programming about the communities themselves. Local programming is an increasingly rare commodity in a Nation that is dominated by national program services and concentrated ownership of the media.

For over 30 years, CPB appropriations have been enacted 2 years in advance. This insulation has allowed public broadcasting to grow into a respected, independent, national resource that leverages its Federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the Federal funds. Most importantly, the insulation that advance funding provides "go[es] a long way toward eliminating both the risk of and the appearance of undue interference with and control of public broadcasting." (House Report 94-245.)

For the last few years, CPB has increased support to rural stations and committed resources to help public radio take advantage of new technologies such as the Internet, satellite radio and digital broadcasting. We commend these activities which we feel provide better service to the American people but want to be sure that the smaller stations with more limited resources are not left out of this technological transition. We ask that the subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system utilize the new technologies, particularly rural and minority stations.

NFCB commends CPB for the leadership it has shown in supporting and fostering the programming services to Latino stations and to Native American stations. For example, Satélite Radio Bilingüe provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues in Spanish of particular interest to the Latino population. At the same time, Native Voice One (NV1) is distributing programming for the Native American stations. There are now over 33 stations controlled by and serving Native Americans.

Two years ago CPB funded the establishment of the Center for Native American Public Radio (CNAPR). After 2 years in operation, CNAPR has helped with the renewal of licenses and expansion of the interconnection system to all Native stations and has raised the possibility of Native Nations owning their own, locally controlled station. In the process of this work, it was recognized that radio would not be avail-

able to all Native Nations and broadband and other new technologies would be necessary. CNAPR has been repositioned as Native Public Media and is working hard to double the number of Native stations within the next 3 years. These stations are critical in serving local isolated communities (all but one are on Indian Reservations) and in preserving cultures that are in danger of being lost. CPB's 2003 assessment recognized that "... Native Radio faces enormous challenges and operates in very difficult environments." CPB funding is critical to these rural, minority stations. CPB's funding of the Intertribal Native Radio Summit in 2001 helped to pull these isolated stations together into a system of stations that can support each other. The CPB assessment goes on to say "Nevertheless, the Native Radio system is relatively new, fragile and still needs help building its capacity at this time in its development." Native Public Media promises to leverage additional, new funding to ensure that these stations can continue to provide essential services to their communities.

CPB also funded a Summit for Latino Public Radio which took place in September 2002 in Rohnert Park, California, home of the first Latino Public Radio station. These Summits have expanded the circle of support for Native and Latino Public Radio and identified projects that will improve efficiency among the stations through collaborations and explore new ways of reaching the target audiences.

CPB plays a very important role for the public and Community Radio system; they are the convener of discussions on critical issues facing us as a system. They support research so that we have a better understanding of how we are serving listeners, and they provide funding for programming, new ventures, expansion to new listeners, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with new distribution technologies and media consolidation. An example of this support is the grant that NCFB received to update and publish our Public Radio Legal Handbook online. This provides easy-to-read information to stations about complying with governmental regulations so that stations can function legally and use their precious resources for programming instead of legal fees.

Finally, Community Radio supports \$40 million in fiscal year 2008 for conversion to digital broadcasting by public radio and television. It is critical that this digital funding be in addition to the on-going operational support that CPB provides. The President's proposal that digital money should be taken from the fiscal year 2008 CPB appropriation would effectively cut stations' grants by over 25 percent. This would have a devastating impact on stations trying to recover from hard economic times. And it would come at a time when the local voices of community and public radio are especially important to notify and support people during emergency situations and to help communities deal with the loss of loved ones—things that commercial radio is no longer able to do because of media consolidation.

While public television's digital conversion needs are mandated by the FCC, public radio is converting to digital to provide more public service and to keep up with commercial radio. The Federal Communications Commission has approved a standard for digital radio transmission and to allow multicasting. CPB has provided funding for 554 transmitters to convert to digital and is working with radio transmitter and receiver manufacturers to build in the capacity to provide a second channel of programming. Most exciting to public and community radio is the encouraging results of tests that National Public Radio has conducted, with funding from CPB, that indicate that stations can broadcast at least three high-quality signals, even while they continue to provide the analog signal. The development of second and third audio channels will potentially double or triple the service that public radio can provide, particularly in service to unserved and underserved communities. This initial funding still leaves nearly 250 radio transmitters that will ultimately need to convert to digital or be left behind.

Federal funds distributed by the CPB should be available to all public radio stations eligible for Federal equipment support through the Public Telecommunications Facilities Program (PTFP) of the National Telecommunications and Information Agency of the Department of Commerce. In previous years, Federal support for public radio has been distributed through the PTFP grant program. The PTFP criteria for funding are exacting, but allow for wider participation among public stations. Stations eligible for PTFP funding and not for CPB funding include small-budget, rural and minority controlled stations and the new Low Power FM service.

Community Radio strongly supports funding for the public radio interconnection system. Public Radio pioneered the use of satellite technology to distribute programming. The new ContentDepot system that the Public Radio Satellite System is launching continues this tradition of cutting edge technology. The satellite capacity that supports this system must be renewed and upgrades are necessary at the sta-

tions and the network operations level. Interconnection is vital to the delivery of the high quality programming that public broadcasting provides to the American people.

This is a period of tremendous change. Digital is transforming the way we do things; new distribution avenues like digital satellite broadcasting and the Internet are changing how we define the business we are in; and, the concentration of ownership in commercial radio makes public radio in general, and Community Radio in particular, more important as a local voice than we have ever been. New Low Power FM stations are providing new local voices in their communities. Community radio is providing essential local emergency information, programming about the local impact of the major global events taking place, culturally appropriate information and entertainment in the language of the native culture, as well as helping to preserve cultures that are in danger of dying out. During the natural disasters of the last couple of years, radio proved once again to be the most dependable and available medium to get emergency information to the public.

During these challenging times, the role of CPB as a convener of the system becomes even more important. The funding that it provides will allow the smaller stations to participate along with the larger stations which have more resources, as we move into a new era of communications.

Thank you for your consideration of our testimony.

#### PREPARED STATEMENT OF THE NIH TASK FORCE OF THE BIOENGINEERING DIVISION

The NIH Task Force of the Bioengineering Division of the Basic Engineering Group of the Council on Engineering of ASME ("Task Force"), is pleased to provide comments on the bioengineering-related programs in the National Institutes of Health (NIH) fiscal year 2008 budget request. The ASME Bioengineering Division is focused on the application of mechanical engineering knowledge, skills and principles to the conception, design, development, analysis and operation of biomechanical systems.

#### IMPORTANCE OF BIOENGINEERING

Bioengineering is an interdisciplinary field that applies physical, chemical and mathematical sciences and engineering principles to the study of biology, medicine, behavior, and health. It advances knowledge from the molecular to the organ systems level, and develops new and novel biologics, materials processes, implants, devices, and informatics approaches for the prevention, diagnosis, and treatment of disease, for patient rehabilitation, and for improving health. Bioengineers have employed mechanical engineering principles in the development of many life-saving and life-improving technologies, such as the artificial heart, prosthetic joints and numerous rehabilitation technologies.

#### BACKGROUND

The NIH is the world's largest and most eminent organization dedicated to improving health through medical science. During the last 50 years, NIH has played a leading role in the major breakthroughs that have increased average life expectancy by 15 to 20 years.

The NIH is comprised of different Institutes and Centers that support a wide spectrum of research activities including basic research, disease- and treatment-related studies, and epidemiological analyses. The missions of individual Institutes and Centers focus on either a particular organ (e.g. heart, kidney, eye), a given disease (e.g. cancer, infectious diseases, mental illness), or a stage of life (e.g. childhood, old age), or may encompass crosscutting needs (e.g., sequencing of the human genome and the National Institute of Biomedical Imaging and Bioengineering (NIBIB)).

The total fiscal year 2008 NIH budget request is \$28.85 billion, which represents a \$330 million (1.1 percent) reduction from the \$29.18 billion approved in the fiscal year 2007 continuing joint resolution. While the Task Force is grateful to Congress for the unexpected \$600 million boost to NIH as it wrapped up the fiscal year 2007 appropriations, we are greatly concerned about the decrease in funding for fiscal year 2008. Research and development is expected to account for 97 percent of the total fiscal year 2008 NIH budget, or \$28.3 billion. With this, the administration estimates that a total of 10,188 new, competing research project grants (RPGs) could be supported, which is an increase of 566 RPGs over fiscal year 2007. While the overall fiscal year 2008 budget decreased compared to fiscal year 2007, the budgets allotted to some institutes and centers actually increased, while all others decreased. The largest increase went to the National Institute of Allergy and Infec-

tious Disease (NIAID), which will receive \$4.59 billion, a total that includes a \$200 million contribution to the Global Fund for HIV/AIDS.

The NIH Roadmap for biomedical research will receive \$486 million in fiscal year 2008, which is an increase of \$3 million from fiscal year 2007. Each institute and center will be required to contribute 1.3 percent of its fiscal year 2008 budget to the NIH Roadmap initiative. Since all institutes and centers were freed of their obligation to transfer 1.2 percent of their budgets to this initiative in fiscal year 2007, an effective 2.5 percent reduction in the budget of each will hence result.

#### NIBIB RESEARCH FUNDING

The administration's fiscal year 2008 budget requests \$300 million for the NIBIB, an increase of \$4 million or 1.3 percent from the fiscal year 2007 continuing joint resolution. Taking into account the 3.7 percent inflation rate (as estimated by the Bureau of Economic Analysis) this effectively amounts to a decrease in funding by 2.4 percent. However, the number of research project applications to NIBIB continues to grow (a 5 percent increase was noted in fiscal year 2006 over fiscal year 2005, for example). The decrease in the NIBIB budget combined with the increase in the number of NIBIB extramural research grant applications will result in a sharp decrease in the success rate for bioengineering-related grants. In fact, the success rate for applications to the NIBIB is already one of the lowest among all NIH institutes and centers (17 percent in fiscal year 2006 versus 20 percent in fiscal year 2005).

#### TASK FORCE RECOMMENDATIONS

The Task Force is concerned that bioengineering-based research continues to constitute a small portion of the total NIH budget. Yet there is an increasing need for advanced engineering concepts to be applied to basic and translational biomedical problems for the potential of recent biological advances to be realized. Moreover, the United States is rapidly falling behind our counterparts in the European Union and Pacific Rim with regards to bioengineering advances. Our request for increased bioengineering funding addresses these critical issues. The Task Force wishes to emphasize that, in many cases, bioengineering-based solutions to health care problems result in a reduction in health care costs. Therefore, we strongly urge Congress to provide increased funding for bioengineering within the NIBIB and across NIH.

The NIBIB requires exceptional and urgent consideration for funding increases in the coming years due to its fiscal year 2006 application success rate of only 17 percent, which is sure to decrease even further for fiscal year 2007 and fiscal year 2008 given the proposed budget estimates. This rate is below average with respect to the NIH as a whole and is a direct manifestation of the continued growth of the bioengineering field outpacing funding increases to the NIBIB.

While the Task Force supports new Federal proposals that seek to double Federal research and development in the physical sciences over the next decade, we believe that strong Federal support for bioengineering and the life sciences is especially essential to the health and competitiveness of the United States. The disturbing trend in the inflation rate outpacing the NIBIB budget increase rate will begin to reverse the tremendous gains the United States has made in the bioengineering field over the last decade. Four years of falling budgets are a sharp contrast from the 15 percent annual increases during the NIH doubling period and will have a long-lasting, deleterious impact.

ASME International is a non-profit technical and educational organization with 125,000 members worldwide. The Society's members work in all sectors of the economy, including industry, academic, and government. This statement represents the views of the ASME NIH Task Force of the Bioengineering Division and is not necessarily a position of ASME as a whole.

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#### PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing is the sole organization representing leaders in nursing education and nurse faculty across all the types of nursing programs in the United States. With more than 1,100 nursing schools and health care agencies, some 20,000 individual members comprising nurses, educators, administrators, public members, and 18 constituent leagues, the National League for Nursing is the premier organization—established 114 years ago—dedicated to excellence in nursing education that prepares the nursing workforce to meet the needs of our diverse populations in an ever-changing health care environment. The NLN appreciates this opportunity to discuss the status of nursing education and the damage that could

ensue to patients and our Nation's health care by the ill-considered cuts aimed at Title VIII.

The NLN endorses the subcommittee's past policy strategies for health care capacity-building through nursing education. We likewise respect your recognition of the requisite role nurses play in the delivery of cost-efficient health care services and the generation of quality health outcomes.

We are disturbed, however, that the 7-year and counting nursing shortage is outpacing the level of Federal resources and investments that have been expended by Congress to help alleviate the nationwide nursing scarcity. The NLN is gravely concerned that the administration's proposed fiscal year 2008 appropriations for nursing education are inconsistent with the health care reality facing our Nation. The President's budget proposes a decrease of funding of \$44 million (or 29 percent) for the Title VIII—Nursing Workforce Development Programs. This budget cut will diminish training and development, a shortsighted and hazardous course of action that potentially further jeopardizes the delivery of health care for the people in the United States.

As the nursing community has pointed out many times before, more than three decades ago during another less serious nursing shortage, Congress appropriated \$153 million for nurse education programs. In today's dollars, that amount would be worth more than \$615 million—four times the amount the Federal Government currently is spending on Title VIII programs.

The National League for Nursing contends that the Federal strategy should be to broaden, not curtail, Title VIII initiatives by increasing investments to be consistent with national demand. We urge the subcommittee to fund the Title VIII programs at a minimum level of \$200 million for fiscal year 2008. The NLN also advocates that section 811 of Title VIII—Advanced Education Nursing Program—be restored and funded at an augmented level equal to the other Title VIII programs.

#### NURSE SHORTAGE AFFECTED BY FACULTY SHORTAGE

The subcommittee is well aware that today's nursing shortage is real and unique from any experienced in the past with an aging workforce and too few people entering the profession at the rate necessary to meet growing health care requirements. NLN research provides evidence of a strong correlation between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new registered nurses (RNs). Without faculty to educate our future nurses, the shortage cannot be resolved.

*The NLN's Nursing Data Review 2004–2005.*—Baccalaureate, Associate Degree, and Diploma Program revealed that graduations from RN programs contributed an estimated 84,878 additional prospective nurses to the RN labor supply falling far short of the Nation's demands. In its biennial 10-year employment projections for 2004–2014, the U.S. Department of Labor's Bureau of Labor Statistics (BLS) reported that over the next 10 years, about 70,000 new RN jobs and 50,000 replacement jobs will accrue each year, for a total of 120,000 RN job openings per year. Multiply that annual sum by 10 years, and BLS's model-based findings estimate that 1.2 million new RN workers will be needed from 2004–2014. This growth represents a 29 percent projected change over the next 10 years.

The NLN's 2004–2005 data review shows that nursing school applications surged in recent years, rising more than 59 percent over the past decade. The 2004–2005 academic year was no exception as almost 25,000 additional applications were submitted to nursing schools at all degree levels. Nonetheless, an estimated 147,000 qualified applications were turned away owing in large part to the lack of faculty necessary to teach additional students. Alarming too, this NLN review determined that new admissions fell by more than 27 percent in 2004–2005 after 2 years of reported increases. The significant dip in admissions seems to mark a turning point, reinforcing that a key priority in tackling the nurse shortage has to be scaling up the capacity to accept qualified applicants.

#### TRENDS STRESSING FACULTY SHORTAGE

It is not surprising that the problem of nurse faculty vacancies often is described as acute and as exacerbating the national nurse-workforce shortfall. The NLN's research, reported in its *Nurse Educators 2006: A Report of the Faculty Census Survey of RN and Graduate Programs*, indicated that the nurse faculty vacancies in the United States continued to grow even as the numbers of full- and part-time educators increased. The estimated number of budgeted, unfilled, full-time positions countrywide in 2006 was 1,390. This number represents a 7.9 percent vacancy rate in baccalaureate and higher degree programs, which is an increase of 32 percent

since 2002; and a 5.6 percent vacancy rate in associate degree programs, which translates to a 10 percent rise in the same period.

The data in the 2006 faculty census survey describe several trends, of which the following three are critical:

#### AGING OF THE FACULTY POPULATION

Nursing programs responding to the survey indicated that almost two-thirds of all full-time nurse faculty members were 45- to 60-years old and likely to retire in the next 5 to 15 years. A mean of 1.4 full-time faculty members per program left their positions in 2006, with 24 percent of these departures due to retirement. It is an open question where schools of nursing will find replacements for these experienced individuals.

#### DECREASE IN DOCTORALLY PREPARED FACULTY

Data show that nurse faculty are less well-credentialed in 2006 than they were 4 years earlier when the last NLN faculty census was conducted. A little over 43 percent of full-time baccalaureate and higher degree program faculty hold earned doctorates; whereas only 6.6 percent of associate degree program full-time faculty and 0.7 percent of diploma program full-time faculty are doctorally prepared. The overwhelming majority of the full-time faculty in associate degree (83 percent) and diploma (92.6 percent) programs hold the master's degree as their highest earned credential. The master's degree was the most common credential among part-time faculty members.

#### INCREASE IN PART-TIME FACULTY

Nearly 45 percent of the estimated mean number of faculty full-time equivalents are part-time faculty. Nationwide, the mean number of faculty members per institution had grown to 14.9 full-time and 12.1 part-time faculty in 2006, compared to 12.3 full-time and 7.4 part-time in 2002. The estimated number of part-time baccalaureate faculty has grown 72.5 percent since 2002. Over 58 percent of baccalaureate and higher degree programs and almost half of associate degree programs (47.5 percent) reported hiring part-time faculty as their primary strategy to compensate for unfilled, budgeted, full-time positions. While the use of part-time faculty allows for greater flexibility, often they are not an integral part of the design, implementation, and evaluation of the overall nursing program.

#### THE FEDERAL FUNDING REALITY

Today's undersized supply of appropriately prepared nurses and nursing faculty does not bode well for our Nation, where the shortages are deepening health disparities, inflated costs, and poor quality of health care outcomes. Congress moved in the right policy direction in passing the Nurse Reinvestment Act in 2002. That act made Title VIII programs a comprehensive system of capacity-building strategies to develop nurses by providing schools of nursing with grants to strengthen programs, through such activities as faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, and loans, scholarships and services that enable students to overcome obstacles to completing their nursing education programs. Yet, as the HRSA Title VIII data show, it is abundantly clear that Congress must step up in providing critical attention and significantly more funding to this ongoing systemic problem.

*Nursing Education Loan Repayment Program.*—In fiscal year 2005, with 4,465 applicants to the Title VIII Nursing Education Loan Repayment Program, 803 awards were made (599 initial 2-year awards and 204 amendment awards), or 18 percent of applicants received awards. In fiscal year 2006, there were 4,222 applicants to the program; 615 awards were made (373 initial 2-year awards and 242 amendment awards) with 14.6 percent of applicants receiving awards.

*Nursing Scholarship Program.*—In fiscal year 2005, 3,482 applications were submitted to the Nursing Scholarship Program, and 212 awards, or 6.1 percent of the applicants received scholarships. In fiscal year 2006, there were 3,320 applicants to the same program and 218, or 6.6 percent, awards were.

*Advanced Education Nursing (AEN) Program.*—This program supports the graduate education that is the foundation to professional development of advanced practice nurses, whether with clinical specialties or with a specialty in teaching. In fiscal year 2005, AEN supported 11,949 graduate nursing students across the specialties. The President's proposed fiscal year 2008 budget eliminates this program, which is fundamental to appropriately preparing future nursing faculty, the engine of the workforce pipeline. AEN must be restored and fully funded in order to prevent the

Nation from losing ground in the effort to remedy the nurse and nurse faculty shortages.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

We would be remiss in not acknowledging that nursing research is an integral part of the effectiveness of nursing care. NINR provides the knowledge base for improving the quality of patient care and reducing health care costs and demands. Critical to enhancing research within the nursing profession is the infrastructure development that increases the pool of nurse investigators and nurse educators, expands programs to develop partnerships between research-intensive environments and smaller colleges and universities, and promotes career development for minority researchers. Yet, as noted by the expanding list of non-nursing journals that publish the investigator findings of NINR-sponsored research, an investment in NINR goes far beyond just the nursing community and produces research results for all health care providers.

The relatively small investment made by the Federal Government in NINR is well justified for the outcomes received. For example, NINR has supported research that:

- Led to nursing intervention enabling excellent metabolic control in diabetic adolescents;
- Devised ways to sustain reduced high blood pressure in young African-American men;
- Reduced the burdens of caregivers of persons with dementia or other chronic care needs; and
- Developed a successful, national model for Spanish speakers in a community-based Arthritis Self-Management Program.

As the only organization that collects data across all levels of the nursing education pipeline, the NLN can state with authority that the nursing shortage in this country will not be reversed until the concurrent shortage of qualified nurse educators is addressed. Without adequate faculty, there are simply too few spots in nursing education programs to train all the qualified applicants out there. This challenge requires millions of dollars of increased funding for the professional development of nurses. The NLN urges Congress to strengthen existing Title VIII nurse education programs by funding them at a minimum level of \$200 million for fiscal year 2008.

Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care.

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#### PREPARED STATEMENT OF THE NATIONAL MARFAN FOUNDATION

Chairman Harkin, ranking member Specter, and members of the subcommittee, the National Marfan Foundation thanks you for the opportunity to submit testimony regarding the fiscal year 2008 budget for the National Heart, Lung and Blood Institute, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and the Centers for Disease Control and Prevention. We are extremely grateful for the subcommittee's strong support of the NIH and CDC, particularly as it relates to life threatening genetic disorders such as Marfan syndrome. Thanks to your leadership, we are at a time of unprecedented hope for Marfan syndrome patients and their families.

It is estimated that 200,000 people in the United States are affected by the Marfan syndrome or a related disorder. Marfan syndrome is a genetic disorder of the connective tissue that manifests itself in many areas of body, including the heart, eyes, skeleton, lungs and blood vessels. It is a progressive condition that can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome however, is a weakening of the aorta. The aorta is the largest artery that takes oxygenated blood to the body from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Fortunately, early surgical intervention can prevent a dissection and strengthen the aorta and the aortic valves. If preventive surgery is performed before a dissection occurs, the success rate of the procedure is over 95 percent. Unfortunately, if surgery is initiated after a dissection has occurred, the success rate drops below 50 percent. Aortic dissection is a leading killer in the United States, and 20 percent of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication.

Fortunately, new research offers hope that a commonly prescribed blood pressure medication, losartan, might be effective in preventing this frequent and devastating event.

#### NATIONAL HEART LUNG AND BLOOD INSTITUTE

As NHLBI Director Dr. Elizabeth Nabel told the subcommittee during her appearance at the April 20th hearing on the "Burden of Chronic Disease" there is landmark clinical trial underway sponsored by NHLBI's Pediatric Heart Network to determine the effects of losartan on aortic growth:

"After the discovery that Marfan syndrome is associated with the mutation in the gene encoding a protein called fibrillin-1, researchers tried for many years, without success, to develop treatment strategies that involved repair or replacement of fibrillin-1. Recently, a major breakthrough occurred with the discovery that one of the functions of fibrillin-1 is to bind to another protein, TGF-beta, and regulate its effects. After careful analysis revealed aberrant TGF-beta activity in patients with Marfan syndrome, researchers began to concentrate on treating Marfan syndrome by normalizing the activity of TGF-beta. Losartan, which is known to affect TGF-beta activity, was tested in a mouse model of Marfan syndrome. The results, published only last April, showed that drug was remarkably effective in blocking the development of aortic aneurysms, as well as lung defects associated with the syndrome.

Based on this promising finding, the NHLBI Pediatric Heart Network, is now undertaking a clinical trial of losartan in patients with Marfan syndrome. About 600 patients aged 6 months to 25 years will be enrolled and followed for 3 years. This development illustrates the outstanding value of basic science discoveries, and identifying new directions for clinical applications. Moreover, the ability to organize and initiate a clinical trial within months of such a discovery is testimony to effectiveness of the NHLBI Network in providing the infrastructure and expertise to capitalize on new findings as they emerge."

Dr. Hal Dietz, the Victor A. McKusick professor of genetics in the McKusick-Nathans Institute of Genetic Medicine at the Johns Hopkins University School of Medicine, and the director of the William S. Smilow Center for Marfan Syndrome Research, is the driving force behind this groundbreaking research. Dr. Dietz uncovered the role that fibrillin-1 and TGF-beta play in aortic enlargement, and demonstrated the benefits of losartan in halting aortic growth in mice. He is the reason we have reached this time of such promise, and we are proud to have supported his cutting-edge research for many years.

We are also extremely grateful to Dr. Nabel and her colleagues at NHLBI for their leadership in advancing the losartan clinical trial. The Pediatric Heart Network, lead by Dr. Lynn Mahony and Dr. Gail Pearson, has demonstrated tremendous skill and dedication in facilitating this complex trial in a very short timeframe. We deeply value their hard work and commitment. NMF is a proud partner with NHLBI in supporting this promising research. The Foundation is actively supporting patient travel costs, and funding ancillary studies to the trial focused on additional manifestations of the Marfan syndrome that might be impacted losartan.

Finally, we are excited that NHLBI has formed a "Working Group on Research in Marfan Syndrome and Related Conditions" jointly sponsored by the NMF. The panel is chaired by Dr. Dietz and comprised of experts in all aspects of basic and clinical science related to the syndrome. The mission of the Working Group is to identify current research opportunities and challenges with a 5-10 year horizon, and to make recommendations for areas that require leadership by the NHLBI in order to move forward. We look forward to partnering with NHLBI to advance the goals outlined by the Working Group.

In order to support the important mission of the NHLBI, and its activities related to Marfan syndrome, NMF joins with the Ad Hoc Group for Medical Research, the Campaign for Medical Research, the Federation of American Societies for Experimental Biology, the National Health Council, and Research!America in recommending a 6.7 percent for NIH overall and NHLBI specifically in fiscal year 2008.

#### NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

NMF is proud of its longstanding partnership with the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director and has generously supported several "Conferences on Heritable Disorders of Connective Tissue." Moreover, the Institute has provided invaluable support for Dr. Dietz's mouse model studies. The discoveries of fibrillin-1, TGF-beta, and their role

in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS.

As the losartan clinical trial moves forward, we hope to expand our partnership with NIAMS to support ancillary studies that fall under the mission and jurisdiction of the Institute. One of the areas of great interest to researchers and patients, is the role that losartan may play in strengthening muscle tissue in Marfan patients. In response to our request for proposals for ancillary studies grants, NMF received applications focused on this area that scored extremely well under the peer review of our Scientific Advisory Board. We appreciate the subcommittee's ongoing support of NIAMS and our collaboration with the Institute on these emerging research opportunities.

To support the mission of the Institute in fiscal year 2008, NMF recommends a 6.7 percent increase for NIAMS.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

We are grateful for the subcommittee's encouragement last year of collaborations between the CDC and the Marfan syndrome community. One of the most important things we can do to prevent untimely deaths from aortic aneurysms is to increase awareness of Marfan syndrome and related connective tissue disorders. Education and prevention are two of the cornerstone missions of the Foundation. However, despite our efforts to raise awareness among the general public and the health care community, we know of too many families who have lost a loved one because they did not know that they were affected.

Recently, the NMF leadership traveled to Atlanta to visit with the Centers for Disease Control and Prevention to explore potential partnerships in the area of awareness and prevention of aortic dissections. We look forward to working with the National Center on Birth Defects and Developmental Disabilities (NCBDD) to prevent needless loss of life from the cardiovascular complications associated with Marfan syndrome. We applaud the leadership of the NCBDD's Division of Human Development and Disability for their interest in this area and appreciate the subcommittee's support of this partnership. We have discussed a number of potential collaborations with the CDC focused on the need for early diagnosis and treatment of Marfan syndrome, in order to enhance the quality and length of life for patients.

In order to support the important work of the CDC, NMF joins with the "CDC Coalition" in recommending an appropriation of \$10.7 billion for the agency in fiscal year 2008. We would also encourage a corresponding percentage increase for the NCBDD and its Division of Human Development and Disability.

#### ABOUT THE NATIONAL MARFAN FOUNDATION

The NMF is a non-profit voluntary health organization founded in 1981. NMF is dedicated to saving lives and improving the quality of life for individuals and families affected by the Marfan syndrome and related disorders. The Foundation has three major goals: (i) to provide accurate and timely information about the Marfan syndrome to affected individuals, family members, physicians and other health professionals; (ii) to provide a means for those with Marfan syndrome and their relatives to share in experiences, to support one another and to improve their medical care and (iii) to support and foster research.

#### PREPARED STATEMENT OF THE ARCH NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair of the ARCH National Respite Coalition, a network of respite providers, family caregivers, State and local agencies and organizations across the United States who support respite. This statement is presented on behalf of the undersigned organizations, many of which are members of the Lifespan Respite Task Force, a coalition of over 80 national and more than 100 State and local groups who supported the passage of the Lifespan Respite Care Act (Public Law 109-442). Together, we are requesting that the subcommittee include funding for the newly enacted Lifespan Respite Care Act in the fiscal year 2008 Labor, HHS and Education Appropriations bill at its modestly authorized level of \$40,000,000. We join the 17 Members of the Senate who, along with Senator Hillary Rodham Clinton (D-NY) and Senator John Warner (R-VA), are sending a letter to the subcommittee making this same request.

#### WHO NEEDS RESPITE?

A national survey found that 44 million family caregivers are providing care to individuals over age 18 with disabilities or chronic conditions (National Alliance for

Caregiving [NAC] and AARP, 2004). In 2001, the last year Federal data were collected, 9,400,000 children under age 18 were identified with chronic or disabling conditions (National Survey of Children with Special Health Care Needs, U.S. Health Resources and Services Administration, 2001). These surveys suggest that a conservative estimate of the Nation's family caregivers probably exceeds 50 million.

Compound this picture with the growing number of caregivers known as the "sandwich generation" caring for young children as well as an aging family member. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition to a parent or other relative with a disability. And in the United States, 6,700,000 children, with and without disabilities, are in the primary custody of an aging grandparent or other relative other than their parents.

These family caregivers are providing about 80 percent of all long-term care in the United States. It has been estimated that in the United States these family caregivers provide \$306,000,000,000 in uncompensated care, an amount comparable to Medicare spending in 2004 and more than twice what is spent nationwide on nursing homes and paid home care combined (Presentation by P.S Arno, PhD, Albert Einstein College of Medicine, January 2006).

#### WHAT IS RESPITE NEED?

State and local surveys have shown respite to be the most frequently requested service of the Nation's family caregivers, including the most recent study, "Evercare Study of Caregivers in Decline" (Evercare and NAC, 2006). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the Nation's family caregivers. The 2004 survey of caregivers found that despite the fact that the most frequently reported unmet needs were "finding time for myself," (35 percent), "managing emotional and physical stress" (29 percent), and "balancing work and family responsibilities" (29 percent), only 5 percent of family caregivers were receiving respite (NAC and AARP, 2004).

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even when respite is an allowable funded service, a critically short supply of well trained respite providers may prohibit a family from making use of a service they so desperately need.

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. In the last 15 years, we suspect that not too much has changed. A recent study conducted by the Family Caregiver Alliance identified 150 family caregiver support programs in all 50 States and Washington, DC funded with State-only or State/Federal dollars. Most of the funding comes through the Federal National Family Caregiver Support Program. As a result, programs are administered by local area agencies on aging and primarily serve the elderly. And again, some programs provide only limited respite, if at all. Only about one-third of these 150 identified programs serve caregivers who provide care to adults age 18–60 who must meet stringent eligibility criteria. As the report concluded, "State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the States."

The 25 State respite coalitions and other National Respite Network members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm.

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. Three-fifths of family caregivers age 19–64 surveyed recently by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers (Ho, Collins, Davis and Doty, 2005). A study of elderly spousal caregivers (aged 66–96) found that caregivers who experience caregiving-related stress have a 63 percent higher mortality rate than noncaregivers of the same age (Schulz and Beach, December 1999).

Supports that would ease their burden, most importantly respite care, are too often out of reach or completely unavailable. Even the simple things we take for granted, like getting enough rest or going shopping, become rare and precious events. One Massachusetts mother of a seriously ill child spoke to the demands of constant caregiving: "I recall begging for some type of in-home support. It was during this period when I fell asleep twice while driving on the Massachusetts Turn-

pike on the way to appointments at Children's Hospital. The lack of respite put our lives and the lives of everyone driving near me at risk."

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for. A mother of a 12-year-old with autism was denied additional respite by her State DD (Developmental Disability) agency because she was not a single mother, was not at poverty level, wasn't exhibiting any emotional or physical conditions herself, and had only one child with a disability. As she told us, "Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service."

For the millions of families of children with disabilities, respite has been an actual lifesaver. However, for many of these families, their children will age out of the system when they turn 21 and they will lose many of the services, such as respite, that they currently receive. In fact, 46 percent of U.S. State units on aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities. An Alabama mom of a 19-year-old-daughter with multiple disabilities who requires constant care recently told us about her fears at a respite summit in Alabama. "My daughter Casey has cerebral palsy, she does not communicate, she is incontinent she eats a pureed diet, she utilizes a wheelchair, she is unable to bathe or dress herself. At 5 feet 5 inches and 87 pounds I carry her from her bedroom to the bathroom to bathe her, and back again to dress her. Without respite services, I do not think I could continue to provide the necessary long-term care that is required for my daughter. As I age, I do wonder how much longer I will be able to maintain my daily ritual as my daughter's primary caregiver."

Disparate and inadequate funding streams exist for respite in many States. But even under the Medicaid program, respite is allowable only through State waivers for home and community-based care. Under these waivers, respite services are capped and limited to narrow eligibility categories. Long waiting lists are the norm.

Respite may not exist at all in some States for adult children with disabilities still living at home, or individuals under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions. In Tennessee, a young woman in her twenties gave up school, career and a relationship to move in and take care of her 53 year-old mom with MS when her dad left because of the strain of caregiving. She went for years providing constant care to her mom with almost no support. Now 31, she wrote, "And I was young—I still am—and I have the energy, but—it starts to weigh. Because we've been able to have respite care, we've developed a small pool of people and friends that will also come and stand in. And it has made all the difference."

#### RESPITE BENEFITS FAMILIES AND IS COST SAVING

Respite has been shown to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability.

The budgetary benefits that accrue because of respite are just as compelling, especially in the policy arena. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save government long-term care programs thousands of dollars. Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (fiscal year 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than 1 year, the number of hospitalizations decreased by 75 percent, physician visits decreased by 64 percent, and antibiotics use decreased by 71 percent (Mausner, S., 1995).

In the private sector, a study by Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17,100,000,000 to \$33,600,000,000 per year in lost productivity of family caregivers (MetLife and National Alliance for Caregiving, 2006). In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999) Offering respite to working family caregivers could help improve job performance and employers could potentially save billions.

## LIFESPAN RESPITE CARE PROGRAM WILL HELP

The Lifespan Respite Care Act is based on the success of statewide Lifespan Respite programs in four States: Oregon, Nebraska, Wisconsin and Oklahoma. Michigan passed State Lifespan Respite legislation in 2004 but has not provided the funding to implement the program, and a State Lifespan Respite bill is currently pending in the Arizona State legislature.

Lifespan Respite, which is a coordinated system of community-based respite services, helps States use limited resources across age and disability groups more effectively, instead of each separate State agency or community-based organization being forced to constantly reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and the savings used to fund new respite services for families who may not currently qualify for any existing Federal or State program.

The State Lifespan Respite programs provide best practices on which to build a national respite policy. The programs have been recognized by prominent policy organizations, including the National Conference of State Legislatures, which recommended the Nebraska program as a model for State solutions to community-based long-term care. The National Governors Association and the President's Committee for People with Intellectual Disabilities also have highlighted lifespan respite systems as viable solutions. And most recently, the White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress.

The purpose of the new law is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, States would be required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services. Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

The Federal Lifespan Respite program would be administered by the U.S. Department of Health and Human Services [HHS], which would provide competitive grants to statewide agencies through Aging and Disability Resource Centers working in collaboration with State respite coalitions or other State respite organizations. The program is authorized at \$40,000,000 in fiscal year 2008 rising to \$95,000,000 in fiscal year 2011.

No other Federal program mandates respite as its sole focus. No other Federal program would help ensure respite quality or choice, and no current Federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include \$40,000,000 in the fiscal year 2008 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated in the States and more families, with access to respite, will be able to continue to play the significant role in long-term care that they are fulfilling today.

## NATIONAL ORGANIZATIONS

American Association of People with Disabilities; American Association on Intellectual and Developmental Disabilities; American Dance Therapy Association; American Network of Community Options and Resources; American Psychological Association; Association of University Centers on Disabilities; Autism Society of America; Bazelon Center for Mental Health Law; Christopher and Dana Reeve Foundation; Chronic Illness Coalition; Easter Seals; Epilepsy Foundation; Family Voices; Generations United; National Association of Councils on Developmental Disabilities; National Association for Home Care and Hospice; National Association of Social Workers; National Association of State Head Injury Administrators; National Council on Aging; National Down Syndrome Congress; National Down Syndrome Society; National Family Caregivers Association; National Gerontological Nursing Association; National Multiple Sclerosis Society; National Organization For Empowering Caregivers; National Rehabilitation Association; National Respite Coalition; National Spinal Cord Injury Association; Older Women's League; Paralyzed Veterans of America; The ALS Association; The Arc of the United States; United Cerebral Palsy; Well Spouse Association; Wilson's Disease Association.

## STATE AND LOCAL ORGANIZATIONS

Alabama Lifespan Respite Resource Network; Allegheny County Respite Care Coalition, Pittsburgh, PA; Arizona Lifespan Respite Coalition (in formation); Catholic

Family and Child Services, Yakima, WA; East Central Alabama United Cerebral Palsy; Easter Seals of Southern Georgia; Families Together, Inc., Wichita, Kansas; Family Voices Vermont; Illinois Respite Coalition; Iowa Respite and Crisis Care Coalition; Kansas Respite Coalition; Louisiana Developmental Disabilities Council; Maryland Respite Care Coalition; Michigan Respite Resource Network; Nebraska Respite Coalition; New Jersey Family Support Center; New Jersey Lifespan Respite Task Force; North Carolina Respite and Crisis Care Coalition; Oklahoma Respite Resource Network; Parent to Parent of Vermont; Partnership for People with Disabilities, Virginia Commonwealth University; Pennsylvania Respite Coalition; Respite and Crisis Care Coalition of Washington; Respite Care Association of Wisconsin; South Carolina Respite Coalition; Tennessee Respite Coalition; Tennessee Voices for Children; The Arc of King County, WA; United Cerebral Palsy of Huntsville and Tennessee Valley, Huntsville, AL; United Cerebral Palsy of Pennsylvania; and Virginia Respite Resource Project.

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#### PREPARED STATEMENT OF THE NATIONAL SLEEP FOUNDATION

##### SUMMARY OF FISCAL YEAR 2008 RECOMMENDATIONS

Provide a \$10,000,000 increase in funding in fiscal year 2008 to the Centers for Disease Control and Prevention (CDC) to undertake data collection activities and create awareness and training programs related to sleep, sleep disorders and the consequences of sleep deprivation to improve public health and safety.

Encourage CDC to continue to take a leadership role in partnering with other Federal agencies and voluntary health organizations in the National Sleep Awareness Roundtable to create collaborative sleep education and public awareness initiatives. In view of CDC's success with similar initiatives, encourage the CDC to financially support the Roundtable and its initiatives.

Provide direction and funding of \$1,000,000 to United States Surgeon General to develop and implement steps leading to the development of a report on sleep and sleep disorders in order to call attention to the public health impact of inadequate and disorder sleep in order to protect and advance the health and safety of the Nation.

Mr. Chairman and members of the subcommittee, thank you for allowing me to submit testimony on behalf of the National Sleep Foundation (NSF). I am Dr. Barbara Phillips, Chair of the NSF Board of Directors and professor at the University of Kentucky College of Health, Department of Preventive Medicine. NSF is an independent, non-profit organization that is dedicated to improving public health and safety by achieving understanding of sleep and sleep disorders, and by supporting sleep-related education, research, and advocacy. We work with sleep specialists and other health care professionals, researchers, patients and drowsy driving victims throughout the country as well as collaborate with many government, voluntary organizations and corporations to prevent health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. It is estimated that sleep-related problems affect 50 to 70 million Americans of all ages and socioeconomic classes. Sleep disorders are common in both men and women; however, important disparities in prevalence and severity of certain sleep disorders have been identified in minorities and underserved populations. Despite the high prevalence of sleep disorders, the overwhelming majority of sufferers remain undiagnosed and untreated, creating unnecessary public health and safety problems, as well as increased health care expenses. Surveys conducted by the National Sleep Foundation show that more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent have ever initiated such a discussion.

Additionally, Americans are chronically sleep deprived as a result of demanding lifestyles and a lack of education about the impact of sleep loss. Sleepiness affects vigilance, reaction times, learning abilities, alertness, mood, hand-eye coordination, and the accuracy of short-term memory. Sleepiness, as a result of untreated disorders or sleep deprivation, has been identified as the cause of a growing number of on-the-job accidents and automobile crashes.

According to the National Highway Traffic Safety Administration's 2002 National Survey of Distracted and Drowsy Driving Attitudes and Behaviors, an estimated 1.35 million drivers have been involved in a drowsy driving crash in the past 5 years. According to NSF's 2006 Sleep in America poll, 51 percent of all adolescents who drive report that they have driven drowsy at least once in the past year. In

fact, 15 percent of drivers in 10th to 12th grades say they drive drowsy once a week or more! A large number of academic studies have linked work accidents, absenteeism, and poor school performance to sleep deprivation and circadian effects.

The recent Institute of Medicine (IOM) report, *Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem*, found the cumulative effects of sleep loss and sleep disorders represent an under-recognized public health problem and have been associated with a wide range of negative health consequences, including hypertension, diabetes, depression, heart attack, stroke, and at-risk behaviors—all of which represent long-term targets of the Department of Health and Human Services (HHS). Moreover, the personal and national economic impact is staggering. The IOM estimates that the direct and indirect costs associated with sleep disorders and sleep deprivation total hundreds of billions of dollars annually.

Sleep science and government reports have clearly demonstrated the importance of sleep to health, safety, productivity and well-being, yet studies continue to show that millions of Americans are at risk for serious health and safety consequences of untreated sleep disorders and inadequate sleep. Unfortunately, despite recommendations in numerous Federal reports, there are no on-going national educational programs regarding sleep and fatigue issues aimed at the general public, health care professional, underserved communities or at-risk groups.

NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. We must elevate sleep to the top of the national health agenda. We need your help to make this happen.

Our biggest challenge is bridging the gap between the outstanding scientific advances we have seen in recent years and the level of knowledge about sleep held by health care practitioners, educators, employers, and the general public. Because resources are limited and the challenges great, we think creative and new partnerships are needed to fully develop sleep awareness, education, and training initiatives. Consequently, the NSF is spearheading two important initiatives to raise public and physician awareness of the importance of sleep to the health, safety and well-being of the Nation.

First, for the last 3 years, Congress has recommended that the CDC support activities related to sleep and sleep disorders. As a result, CDC's National Center for Chronic Disease Prevention and Health Promotion has been collaborating with more than twenty voluntary organizations and Federal agencies to form the National Sleep Awareness Roundtable (NSART), which was officially launched in March of this year. NSART is currently working through four task forces—public awareness, research, patient access to care, and public policy—to develop a National Action Plan. This document will address what is required to organize a successful collaboration to implement effective public and professional awareness and education initiatives to improve sleep literacy and healthy sleep behaviors. NSART is seeking to expand its membership by reaching out to new organizations and State and Federal agencies that are interested in raising awareness of sleep issues and implementing NSART's National Action Plan.

The CDC has taken initial steps to begin to consider how sleep affects public health issues, but it needs appropriate resources to take additional actions, as recommended by the IOM and other governmental reports. Currently, the CDC budget does not include a line item for sleep-related activities.

With adequate resources, the CDC could:

- Add sleep-related items to established surveillance systems to build the evidence base for the prevalence of sleep disorders and their co-morbidities in order to increase awareness of these issues on the national, State, and local levels.
- Support the development of targeted approaches for delivering messages to promote sleep, along with exercise and nutrition, as a healthy behavior, and for increasing public and professional education and awareness regarding the public health impact of untreated sleep disorders and chronic sleep loss.
- Develop training materials for health care professionals regarding the signs and symptoms of sleep disorders, as well as countermeasures for drowsy driving and workplace accidents related to sleep loss, shift work, and long work hours.
- Increase and enhance fellowship opportunities to attract promising researchers at universities and colleges across the country to conduct epidemiological activities and health cost assessments regarding sleep.

NSF and members of the National Sleep Awareness Roundtable believe that a partnership with CDC is critical to address the public health impact of sleep and sleep disorders. We hope that the committee will provide funding of \$10,000,000 to the CDC to begin programs as outlined here and to support efforts developed by

NSART through a cooperative agreement similar to other roundtables in which CDC participates.

Second, at the National Institutes of Health's Frontiers of Knowledge in Sleep and Sleep Disorders conference in 2004, the U.S. Surgeon General acknowledged widespread illiteracy in our country regarding sleep loss and untreated sleep disorders. He emphasized that sleep problems are easily related to the three top areas of the national health agenda: prevention, preparedness, and health disparities. Prevention of some of our Nation's most pressing health problems would be fostered by attending to sleep disorders. Sleep deprivation and fatigue are major barriers to maximizing preparedness and response in times of crisis. Finally, like many health and safety concerns, access to knowledge and medical care for sleep problems is beyond the reach of many Americans.

For the last 2 years, Congress has directed the Office of the Surgeon General to help promote sleep as a public health concern through the development of a Surgeon General's Report on Sleep and Sleep Disorders, in order to call attention to the importance of sleep and develop strategies to protect and advance the health and safety of the Nation. The Surgeon General has expressed interest in addressing this issue through the development of a conference or workshop on how sleep impacts public health, but currently lacks the funding to proceed.

Therefore, NSF respectfully requests that the committee provide direction and \$1,000,000 in funding to the Office of the Surgeon General to develop a workshop and a call to action related to sleep and public health, in preparation for a Report on Sleep and Sleep Disorders.

The IOM report includes important recommendations that support the spirit of these efforts and other specific actions to be taken by the CDC and the Office of the Surgeon General to raise awareness of sleep health and sleep disorders and to collect surveillance data to evaluate future education and intervention initiatives. CDC and the Surgeon General must receive direction and appropriate funding in order to continue partnering with voluntary health organizations and State and Federal agencies to increase support for initiatives that help ensure the health and safety of all Americans.

Thank you again for the opportunity to present you with this testimony.

#### PREPARED STATEMENT OF THE NATIONAL TECHNICAL INSTITUTE FOR THE DEAF

Mr. Chairman and members of the committee: I am pleased to present the fiscal year 2008 budget request for the National Technical Institute for the Deaf, one of eight colleges of the RIT, in Rochester, NY. We serve the university needs of approximately 1,100 deaf/hard-of-hearing students from across the nation and 150 hearing students, on a campus of over 14,000 students. Created by Congress, we provide postsecondary technical education to prepare deaf/hard-of-hearing students for successful employment.

NTID has fulfilled this mandate with distinction for 39 years.

#### BUDGET REQUEST

NTID's fiscal year 2008 request is \$60,757,000. This consists of \$59,052,000 for continuing operations and \$1,705,000 for construction projects initiating replacement of aging mechanical systems. The NTID request and the President's are shown below.

	Operations	Construction	Total
NTID request .....	\$59,052,000	\$1,705,000	\$60,757,000
President's Request .....	55,349,000	913,000	56,262,000
Difference .....	3,703,000	792,000	4,495,000

We are respectfully requesting that the committee restore the appropriation to the NTID requested level. Our operations request does not include additional funding for new academic programs or headcount. Instead, we are committed to fund all program improvements and increases in headcount, if any, through the reallocation of existing resources.

We commit because we have consistently minimized requests. From fiscal year 2003 to fiscal year 2007 we saved of \$6.2 million by increasing revenues and reducing/reallocating headcounts. These difficult savings controlled budget requests while allowing expansion in areas such as speech-to-text services for deaf/hard-of-hearing students who do not know sign language.

We are proud of those accomplishments; however, those actions leave limited flexibility regarding what we respectfully submit is inadequate funding proposed in the President's budget. Significant reductions threaten our vitality, and leave us with options such as the following:

1. *Not Funding Technology Needs.*—Student curricula demand state-of-the-art technology updates to prepare students for jobs. For deaf/hard-of-hearing students, technology to support the delivery of instruction is critical. We spend \$1,000,000/year for technology; eliminating that would reduce programming development and quality.

2. *Not Supporting Endowment Allocations.*—The Education of the Deaf Act authorizes matching private donations from appropriations, to reduce dependence on Federal funds. In fiscal year 2006, NTID matched over \$900,000; we do not want to stop this practice.

3. *Not Supporting Outreach Efforts, Which Impact Future Enrollment.*—Approximately \$542,000 supports six programs designed to: attract junior/senior high school students to NTID; create a Community College Referral Program; and establish a Summer English Institute. All are designed to increase future enrollments.

4. *It Does Not Include a Fair Labor Standards Act (FLSA) Lawsuit Against RIT With a \$2.5 Million Settlement Proposal Announced in March, 2007.*—It affects 170 current RIT employees including about 140 NTID employees (mostly sign language interpreters), and others who have worked for NTID within the last 6 years. A proportion of the settlement may be paid by NTID in fiscal year 2008; the exact amount is to be determined.

With the reclassification of positions from exempt-from-overtime to non-exempt-from-overtime, we expect an increase in our compensation expenses. The financial impact is to be determined; however, its impact is immediate, beginning April 16, 2007.

5. *It Does Not Recognize the Effect of Inflation and the Impact of Freezing Positions.*—NTID budgeted a 3 percent salary increase in fiscal year 2007, but the RIT increase was 3.5 percent; we follow RIT per our Department of Education agreements. At level fiscal year 2008 funding we will consider freezing open positions, including those we have aggressively filled such as speech-to-text services which expanded in response to an Office of Civil Rights ruling.

NTID expenses are driven by inflationary pressures. We must fund salary, health care, and energy costs increases, and the rising costs of RIT services, which are subject to the same pressures. Taken together, these costs represent over 80 percent of NTID's total expenditures.

The President's request for fiscal year 2008 ignores inflationary increases and returns to fiscal year 2006 levels. Our requested increase of \$3,703,000 in fiscal year 2008 operations over that fiscal year 2006 level is the equivalent of having obtained an increase of 3.3 percent both from fiscal year 2006 to fiscal year 2007 (which we did not receive) and from fiscal year 2007 to fiscal year 2008. We believe these requests are supported by the rationale above on the negative impact of various potential reductions.

Regarding construction, the President's request partially funds the \$1.7 million needed to replace mechanical heating, ventilation, and air-conditioning systems (well past their expected lives in 40 year old buildings) and the delivery of energy to NTID buildings. The systems have been well maintained but on-going maintenance difficulties dictate replacement at this time.

#### ENROLLMENT

Total enrollment is at 1,250 for school year 2006–2007 (fiscal year 2007), and was 1,256 students last year. NTID anticipates maintaining or increasing enrollment for school year 2007–2008 (fiscal year 2008). A 5-year summary of student enrollment follows.

#### NTID ENROLLMENTS—5 YEAR NUMBERS

School Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Subtotal	Interpreting Program	MSSE	Subtotal	
2002–3 .....	1,093	29	16	1,138	65	28	93	1,231
2003–4 .....	1,064	45	41	1,150	92	28	120	1,270
2004–5 .....	1,055	42	49	1,146	100	35	135	1,281
2005–6 .....	1,013	53	38	1,104	116	36	152	1,256
2006–7 .....	1,017	47	31	1,095	130	25	155	1,250

The number of students studying in our interpreting program has grown substantially, the number in our graduate secondary teacher preparation program—MSSE—has fluctuated (totaling both MSSE columns above), and the sub-total of deaf/hard-of-hearing students has declined from 1,138 in 2002–2003 to 1,095 in 2006–2007, a decline of 43 students. However, the decline in enrollment of deaf/hard-of-hearing students parallels almost one-for-one the drop in international students from 90 enrolled in 2002–2003 to 42 enrolled in 2006–2007, a decline of 48 students. A change in the Education of the Deaf Act increased the surcharge on tuition for international students from 50 percent to 100 percent, resulting in the significant decline.

#### INCREASING NUMBERS OF STUDENTS WITH SECONDARY DISABILITIES

NTID is working with significantly increased numbers of students with disabilities in addition to deafness. The table shows the number and percent of students receiving services from the RIT Disability Services Office, which serves students with physical or mental impairments that limit one or more major life activities. Their services assure equal access to education based upon legal foundations established by Federal law—the Rehabilitation Act of 1973 including section 504, and the Americans with Disabilities Act of 1990.

NUMBER AND PERCENT OF STUDENTS RECEIVING SECONDARY DISABILITY SERVICES

Year	Number	Percent
1998–1999 .....	33	3.0
1999–2000 .....	57	5.0
2000–2001 .....	82	7.6
2001–2002 .....	78	7.2
2002–2003 .....	97	8.6
2003–2004 .....	95	8.7
2004–2005 .....	110	10.3
2005–2006 .....	129	12.7

While we are unable to calculate the additional budgetary costs, it is clear that services are increasing significantly year-by-year, with associated increased costs.

#### STUDENT ACCOMPLISHMENTS

Our recently reported placement rate indicates that 95 percent of NTID's fiscal year 2005 graduates in the labor force were employed (using the methodology of the Bureau of Labor Statistics) in jobs commensurate with the level of their academic training. Over the last 5 years, a large proportion (83 percent) were employed in science, engineering, business, and visual communications.

In fiscal year 2005, new research conducted with the Social Security Administration and Cornell University examined 10,196 graduates and withdrawals spanning 25 years. It shows that graduation from NTID has significant economic benefits over a lifetime of work. Baccalaureate graduates earn, on average during their peak earning years, \$12,020 more per year than students who attend, but withdraw without a degree; sub-baccalaureate graduates earn \$4,762 more. Students who withdraw experience twice the rate of unemployment as graduates.

NTID clearly makes a significant, positive difference in the earnings, and in turn in the lives of those who graduate.

While 60 percent of students attending NTID receive benefits through the Supplemental Security Income program (SSI), by the time they are at age 50, less than 3 percent of graduates continue to draw SSI benefits. Graduates also access Social Security Disability Insurance (SSDI), fundamentally an unemployment benefit, at far lesser rates than withdrawals. By age 50, withdrawals were twice as likely to be receiving SSDI as degree graduates.

A large percentage of non-graduates will continue to depend heavily on Federal income support throughout their lives. But NTID graduation significantly reduces dependence on welfare programs. Considering the added taxes graduates pay as a result of their increased earnings, and the savings derived from reduced dependency on the Federal income support programs, the Federal investment in NTID returns significant societal dividends.

#### NTID BACKGROUND

*Academic Programs.*—NTID offers high quality, career-focused, associate degree programs that lead to placement in well-paying technical careers. A cooperative edu-

cation component ties closely to high demand employment opportunities. We are expanding transfer associate degree programs to better serve the higher achieving segment of our student population who seek bachelors and masters degrees in an increasingly demanding marketplace. These transfer programs provide for seamless transition to baccalaureate studies. Finally, we support students in RIT baccalaureate programs. One of NTID's greatest strengths is its outstanding track record of assisting high-potential students to gain admission to and to graduate from the other colleges of RIT at rates that are better than their hearing peers.

*Research.*—The research program and agenda are guided and organized according to these general research areas: Language and Literacy, Teaching and Learning, Socio-cultural Influences, Career Development, Technology Integration, and Institutional Research. All benefit enrolled students as well as deaf/hard-of-hearing adults throughout the country.

*Outreach.*—Extended outreach activities to junior and senior high school students, expand their horizons regarding a college education.

*Student Life.*—The new Student Development Center, funded by a \$2.0 million gift from a private individual and \$1.5 million fiscal year 2005 Federal appropriations has been occupied. Our activities foster student leadership and community service, and providing opportunities to explore other educational interests.

#### SUMMARY

The fiscal year 2008 request will allow NTID to continue its mission of preparing deaf/hard-of-hearing people to enter the workplace and society and compete with their hearing peers. Our alumni have demonstrated that they can achieve full independence and become contributing members of society; they can earn a living and live a satisfying life as a result of the postsecondary education received at NTID. Collaborative research between NTID and the Social Security Administration shows that NTID graduates over their lifetimes are employed at a much higher rates, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in Federal welfare programs.

We are hopeful that the members of the committee will agree that NTID, with its outstanding record of service to deaf/hard-of-hearing people, remains deserving of their support and confidence.

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#### PREPARED STATEMENT OF THE NATIONAL TUBERCULOSIS CONTROLLERS ASSOCIATION

The National Tuberculosis Controllers Association (NTCA) is pleased to submit our recommendations for TB control programs in the Labor Health and Human Services and Education Appropriations subcommittee purview.

The National Tuberculosis Controllers Association (NTCA) is a membership organization composed of persons who are working, or have worked in Tuberculosis Control programs in the United States and its Pacific Affiliated Islands. Membership is also extended to our partners in other TB-related organizations and to any other persons who have interest in Tuberculosis control issues.

The United States is now facing unprecedented threats in our progress towards the goal of eliminating TB and even our fundamental responsibility to control TB, due to regressive cuts to programs that are essential to contain the disease and prevent the creation of new highly dangerous strains of drug resistance.

#### PREVALENCE OF TB IN THE UNITED STATES

Tuberculosis (TB) is a disease caused by a bacterium that is spread through the air—that is, it is spread from person-to-person by sharing the air that we breathe. Infection affects some people immediately, but for many, it becomes “dormant,” to become active at a later time. It is estimated that one-third of the world's population is infected with TB in this latent form, and indeed, these people form a reservoir of a disease that kills more than 2 million adults and children each year (~1 every 15 seconds) and remains the leading cause of human death from an infectious disease today.

In the United States, efforts to control the disease following its resurgence in the early 1990's have created a public health infrastructure that has been able to achieve that goal in many sectors. At the heart of this endeavor is the Centers for Disease and Control's (CDC) Division of TB Elimination (DTBE), which coordinates prevention and control activities to States through cooperative agreement awards to support categorical infrastructure. Following interim analyses, the Institute of Medicine (IOM) declared in its 2000 report, *Ending Neglect, the Elimination of Tuberculosis in the United States*, that TB could be eliminated as a public health problem

in the United States by 2010. The 13,767 cases reported in 2006 represent the lowest absolute number of cases ever recorded in our country. But we are far from TB elimination. The lower numbers have again lulled us into a false sense of security, and as Federal support once again is being withdrawn, we are facing another potential and more dangerous challenge to our public's health.

The majority of U.S. TB cases come from outside U.S. borders. Fifty-five percent of 2006 TB cases were non-U.S. born, but the majority of these individuals have resided in the United States for more than 5 years and are citizens. Twenty States reported increases in TB cases in 2006 over 2005, with the District of Columbia recording the highest TB case rate (12.6/100,000) in the Nation.

White, U.S.-born people no longer make up the majority of TB cases in the United States—TB now embraces racial and ethnic minorities as never before. African Americans have 8 times the risk of developing TB as whites; Hispanics and Asians have 8 and 21 times the risk, respectively. Our health systems have been slow to adapt to the needs of these populations.

#### CHALLENGES TO TB CONTROL

In its November 2005 statement, CDC recognized 5 critical challenges to controlling TB in the United States. Addressing each challenge requires intact and fully functional local public health systems that are able to reach people at-risk, unique to populations in individual States and to the disease. Our State and local TB programs are losing the front-line, experienced staff that provide adequate case management to persons with active (and infectious) TB and ensure safe completion of treatment (at least 6–9 months of multiple medications), preventing the emergence of drug resistance among those who do not take medications appropriately. As programs lose funding, it is these essential, “core” services that are being compromised, or even eliminated entirely.

The Division of TB Elimination has been level-funded for at least 12 years; in 2006, our State and local programs were asked to absorb a real cut of 4.8 percent in Federal funding. The impact has been stealthy, but clear. These are examples:

In Massachusetts, 77 percent of reported TB cases are foreign-born, and among this group, about 95 percent are drug-resistant. The State also has fewer staff resources to handle these cases since nine field staff positions (21 percent of the work force) have been lost since 2002.

In New York City, 1,185 patients had to be managed by 26 fewer nurses and field staff (an 18 percent cut).

California has more than 20 percent of our national cases, 2,800, of whom 78 percent are foreign-born. California reports an 11 percent rate of drug resistance and yet had to deal with a 9 percent reduction in its Federal support versus 2005.

California and New York both reported cases of the new Extensively Drug-Resistant (XDR)-TB strain in 2006. These strains are virtually resistant to current treatment regimens and are associated high levels of mortality.

In December, Dr. Michael Fleenor, Chair of the National Advisory Committee on the Elimination of Tuberculosis, wrote to Secretary Leavitt and to CDC Director Gerberding to express concerns of the Council concerning the current negative impact of these funding reductions and to point out the urgent need to address these concerns in light of the new strains of XDR-TB. XDR-TB is produced by the failure to effectively treat individuals with other multidrug resistant TB (MDR TB) strains. Each of the 118 MDR TB cases reported in the United States in 2005 has the potential to become XDR TB without the expertise and infrastructure to cure the disease through directly observed treatment. Make no mistake—XDRTB is already in the United States and only our public health infrastructure prevents the production of more cases!

The resurgence of tuberculosis and the emergence of Multi-Drug Resistant TB (MDR/TB), organisms resistant to the two most effective drugs in the 1990's resulted from a collapse of the same infrastructure that we have since struggled to re-create, and are in the process of disassembling once again at this very moment. In short, we are being set up to fail. Earlier this year, U.S. Assistant Surgeon General and DTBE Director, Dr. Kenneth Castro warned the TB control community to anticipate a further reduction of 25 percent in Federal support for TB control over the next 5 years. Such a reduction bodes poorly for sustained efforts to control the disease, and, in the face of emerging XDR-TB, is a potential disaster.

There is another lethal disease, to which governmental response was, on balance, both swift and appropriate, and from which we can learn: SARS. XDR-TB is, in many ways imminently more dangerous than SARS. While both are virtually untreatable, have extremely high death rates and are transmissible from person to person, TB unlike SARS, has both a human reservoir and a state of Latent Infec-

tion. TB, both regular and XDR, can lie dormant, only to emerge months or years later and spread person to person. Yet today we are facing funding cutbacks rather than vitally needed increases to keep our defensive infrastructure intact against TB.

In order to put our domestic situation in proper context. Basic and applied research is sorely needed to help us understand the complex interactions between the TB organism and human beings which gives rise to latent and active disease. Research will provide insights as to how we might reduce the length, complexity, and toxicity of our currently limited drugs; it will provide us with tools to diagnose TB disease and dormant infection quickly; and it will help us understand how to reach people at-risk to prevent TB from developing. Laboratories must have better tools to identify and report drug resistance cheaply and quickly. And we must use our understanding and our resources to assist other countries in controlling the disease and preventing the emergence of active disease in those with dormant infection—for the world's problem truly is our problem too.

The CDC DTBE clearly has demonstrated its ability to work closely with State and local public health TB programs to address issues of TB control. This association and cooperative partnership is responsible for the successes we have achieved over the past 15 years and it should be reinforced by assuring adequate support for the unprecedented challenges we are now facing. The current funding level of \$137.4 million for DTBE actually represents a 23 percent decrease over the past decade, adjusted for inflation. The NTCA recommends that the committee adopt the National Coalition for the Elimination of Tuberculosis's recommendation of an increase of \$390.6 million in project funding for the CDC's Division of Tuberculosis Elimination for a total of \$528 million in fiscal year 2008. This includes:

- To Maintain Control of Core Activities and Regional Medical Training and Consultation Centers (RTMCC's)—\$185 million
- Preparedness & Outbreak Response Capacity for XDR TB—\$45 million.
- Accelerating the Decline—\$75 million.
- For Research and Development of New Tools, Drugs and Diagnostics—\$110 million.
- For Intensified Support for Action to Accelerate Control (ISAAC). Includes Enhancements to Surveillance, Laboratory, Border Health, Health Disparities, Evaluation, and Research Translation (Turning Research Into Practice)—\$113 million.

#### CONCLUSION

Clearly, the responsibility for TB control is a shared one. The CDC DTBE has an excellent track record of working closely with State and local health departments, providers and communities; the successful control of TB among residents of New Orleans during the hurricane is a recent example. Without the expertise and public health infrastructure that was in place, the 130 TB cases that were distributed from New Orleans to emergency shelters across the United States would have led to multiple outbreaks of TB. However, the ongoing budget cuts at the CDC directly impair TB prevention and control core activities within the States and seriously compromise a remarkable successful relationship. We have seen this pattern before. We know this will leave us once again at risk of an even more deadly epidemic of tuberculosis. The NCTA appreciates the opportunity to submit this statement to the subcommittee.

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#### PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

##### SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2008

A 6.7 percent increase for the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Continue to expand the NIDDK's Nephrotic Syndrome (NS) and Focal Segmental Glomerulosclerosis (FSGS) research portfolios by aggressively supporting grant proposals in this area and creating a Glomerular Disease Registry.

Encourage the National Center for Minority Health and Health Disparities (NCMHD) to initiate studies into the incidence and cause of NS and FSGS in minority populations.

Mr. Chairman and members of the subcommittee, the NephCure Foundation (NCF) is grateful for the opportunity to present testimony before you. NCF is a non-profit organization that is driven by a panel of respected medical experts and a dedicated band of patients and families that work together to save kidneys and also lives. NCF is the only non-profit organization exclusively devoted to fighting idiopathic nephrotic syndrome (NS) and focal segmental glomerulosclerosis (FSGS).

Now in our sixth year, the NephCure Foundation continues to work tirelessly to support glomerular disease research.

#### FSGS: ONE FAMILY'S STORY

Bradly Grizzard, was diagnosed with focal segmental glomerulosclerosis (FSGS) in 2002. In May of 2005, his mother donated one of her kidneys to him.

FSGS is one of a cluster of glomerular diseases that attack the tiny filtering units contained in each human kidney, known as nephrons. Glomerular disease attacks the portion of the nephron called the glomerulus, scarring and often destroying these filters. Currently, scientists do not know why glomerular injury occurs, and there is no known cure for these diseases.

Upon diagnosis, an FSGS patient's health often takes a rapid downward plunge at and it is extremely difficult to make a comeback. Bradley was a star football player at his high school and was being recruited by college football coaches before FSGS attacked his body. When his kidneys failed, he was forced to give up football, as well as juggle college classes with several hours of dialysis a day. He was lucky that his mother's kidney was a match, but even so, the first few hospitals that they approached refused to perform the transplant. They were eventually able to find a doctor and a hospital that was willing to perform the operation, and the transplanted kidney is now working well. Even though Bradley is now feeling much stronger, he must remain on costly immunosuppressant drugs for the rest of his life. These drugs cause many unpleasant side effects and medical complications.

Sadly, Bradley's story is far from unique. There are thousands of people in this country who have had their lives disrupted due to the sudden onset of FSGS. Furthermore, although kidney transplants have been very successful for thousands of FSGS patients, many patients end up rejecting the transplanted kidney. A large percentage of patients even see the FSGS comes back and attacks the transplanted kidney. In either case, the patient must then again rely on daily dialysis as a means of survival. There are thousands of young people who are in a race against time, hoping for a treatment that will save their lives. The NephCure Foundation today raises its voice to speak for them all, asking you to take specific actions that will aid our mission to find the cause and cure of NS/FSGS.

First and foremost, we join the Ad Hoc Group for Medical Research Funding in asking for a 6.7 percent increase for the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

#### MORE RESEARCH IS NEEDED

Little progress has been made on finding the cause of or the cure for FSGS. Scientists tell NCF that much more research needs to be done on the basic science behind the disease.

NCF is thankful that the NIDDK is continuing to work with us on the FSGS clinical trial. Currently, 150–175 patients nationwide are enrolled in the trial. Recently, the steering committee charged with providing programmatic direction to the trial decided on several changes which would accelerate progress. NCF is also working with the NIDDK to cosponsor ancillary basic biological material studies of the enrolled patients.

NCF is pleased to learn that the NIDDK is intending to re-release the program announcement (PA) entitled, "Exploratory Basic Research in Glomerular Disease" (PA-06-228). After being originally introduced as a R21 PA in March of 2006, PA-06-228 was rescinded along with all other non-clinical R21 programs when they were folded into the general NIH wide solicitation. NCF is optimistic that re-issuing this PA under the RO1 mechanism, as intended, will stimulate significant research into glomerular diseases.

As health information technology continues to advance, disease registries and databases are fast becoming a crucial resource and vital source of information. The basic understanding of numerous conditions has been greatly improved by compiling patient information and disease data. At this time, no such registry exists for glomerular diseases. NCF has been informed by researchers and scientists that such a registry would greatly increase the clinical knowledge of NS and FSGS.

We ask the committee to encourage the NIDDK to help find the cause and the cure for glomerular disease by continuing its support for the FSGS clinical trial and the ancillary basic biological material studies. We also ask the NIDDK to continue to add glomerular disease to program announcements. Additionally, we would like the committee to recommend that the NIDDK place a high priority on any initiatives that seek to establish a glomerular disease registry.

## TOO LITTLE EDUCATION ABOUT A GROWING PROBLEM

When glomerular disease strikes, the resulting nephrotic syndrome causes a loss of protein in the urine and edema. The edema often manifests itself as puffy eyelids, a symptom that many parents and physicians mistake as allergies. With experts projecting a substantial increase in nephrotic syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

NCF has conducted numerous education programs. A national FSGS conference was held in Philadelphia from June 3–4, 2006. This conference sought to provide attendees with the most up to date information on this disease. Through speakers, information sessions, and informal conversations with other patient families, attendees realized that they are not alone and will be further energized for the effort to find a cause and a cure for FSGS.

Also, last summer, the NIDDK sponsored a working group scientific conference. This working group advised NIDDK on animal models, reagents, and other resources for the study of glomerular disease.

NCF also applaud the work of the NIDDK in establishing the National Kidney Disease Education Program (NKDEP), and we seek your support in urging the NIDDK to make sure that glomerular disease remains a focus of the NKDEP.

We ask the committee to encourage the NIDDK to have glomerular disease receive high visibility in its education and outreach efforts, and to continue these efforts in conjunction with the NephCure Foundation's work. These efforts should be targeted towards both physicians and patients.

## GLOMERULAR DISEASE STRIKES MINORITY POPULATIONS

Nephrologists tell NCF that glomerular disease strikes a disproportionate number of African-Americans. No one knows why this is, but some studies have suggested that a genetic sensitivity to sodium may be partly responsible. DNA studies of African Americans who suffer from FSGS may lead to insights that would benefit the thousands of African Americans who suffer from kidney disease.

NCF asks that the NIH pay special attention to why this disease affects minority populations to such a large degree. NCF wishes to work with the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to encourage the creation of programs to study the high incidence of glomerular disease within the African-American population.

There is also evidence to suggest that the incidence of glomerular disease is higher among Hispanic-Americans than in the general population. An article in the February 2006 edition of the NIDDK publication *Recent Advances and Emerging Opportunities*, discussed the case of Frankie Cervantes, a 6 year old boy of Mexican and Panamanian descent. Frankie has FSGS, and like Bradley, received a transplanted kidney from his mother. We applaud the NIDDK for highlighting FSGS in their publication, and for translating the article about Frankie into both English and Spanish. Only through similar efforts at cross-cultural education can the African-American and Hispanic-American communities learn more about glomerular disease.

We ask the committee to join with us in urging the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to collaborate on research that studies the incidence and cause of this disease among minority populations. We also ask that the NIDDK and the NCMHD undertake culturally appropriate efforts aimed at educating minority populations about glomerular disease.

Thank you again for this opportunity and please contact us if you have any questions or require additional information.

## PREPARED STATEMENT OF NTM INFO AND RESEARCH

## AGENCY RECOMMENDATIONS

CDC: NTMIR requests a \$7,000,000 allocation in the budget to enable CDC, Infectious Diseases HIV/AIDS, STD and TB Prevention Program to launch an external partnership to develop and implement a public health education and outreach initiative to promote NTM education for health care providers and the general public. Further NTMIR requests that CDC develop specific epidemiology studies regarding prevalence, geographic, demographic and host specific data regarding NTM infection in the population.

NIH: NTMIR requests an allocation in the budget to enable NIH, NHLBI to advance diagnostics and treatments for patients suffering from pulmonary Nontuber-

culous Mycobacteria (NTM) disease. NTMIR further requests that NHLBI issue a program announcement or other appropriate mechanism to ensure the initiation of grant proposals

NIH: NTMIR requests an allocation in the budget to enable NIH, NIAID to collaborate further with NHLBI, the advocacy community and other Federal agencies to advance the understanding of NTM by establishing a national registry of patients and to issue a program announcement, an NIH partnership funding program or other appropriate mechanism to ensure the initiation of grant proposals and other activities in NTM.

Thank you for the opportunity to submit a statement on behalf of NTM Info & Research and all the patients suffering with pulmonary NTM disease.

#### WHAT IS PULMONARY NONTUBERCULOUS MYCOBACTERIAL DISEASE (NTM)?

NTM is an infectious disease considered to be of environmental origin as these bacteria are ubiquitous in the water and soil that surround us. Although NTM is diagnosed by the same basic test used to diagnose traditional tuberculosis (TB), it is significantly more difficult to treat. NTM progressively diminishes lung capacity, with all the attendant negative consequences in life.

Unfortunately, even though TB has a significantly high profile, NTM does not because education and awareness have been lacking. Furthermore, there is growing evidence that NTM is many times more prevalent than TB in the United States. For example, the State of Florida Infectious Disease Laboratory reports receiving over twice as many specimens that are NTM positive for every one that is positive for TB. Even more startling, the Agency for Health Care Administration for Florida hospital patient discharges shows almost 9 times the number of patients with the primary diagnosis of NTM versus those with TB.

Doctors in leading treating facilities are reporting that even though NTM is not reportable, they are seeing more NTM patients than TB patients. A current report from Toronto, Ontario indicates that the prevalence may be six times higher than the older data we have in the United States.

NTM is not limited to one strain and has certain strains that are inherently resistant to drug therapy, and in all cases multiple drugs are required on a lengthy to permanent basis. A significant number of patients require short- to long-term intravenous medication and this is a particular hardship for the elderly because Medicare does not cover in-home therapy. Medicare recipients must be hospitalized one to three times a week driving treatment costs significantly higher than in alternate settings.

#### NTM INFO & RESEARCH (NTMIR)

NTMIR was founded through a partnership of concerned patients and interested physicians who see increasing numbers of people affected by this devastating disease. NTMIR was created to expand professional awareness, diagnosis and treatment, facilitate research and provide patient support. Our mission is a public/private partnership to advance the science and the outcomes for countless patients with NTM disease.

NTMIR has already demonstrated a track record of success since it commenced its activities just 3 years ago. These include, successful implementation of the NTMInfo.org website and online support group, patient education throughout the country through the replication of an NTM information pamphlet, initiating professional education and Grand Round lectures to increase professional education both for specialists and family physicians, establishment of a partnership of cooperation with public health in the State of Florida and with the American Lung Association of Florida. NTMIR negotiated an agreement between a major pharmaceutical company, the FDA and a division of HRSA to provide an urgently needed drug for patients who could not otherwise obtain it, some of whom might have died without it.

#### *Fern Leitman's Story*

In September 1996, shortly after lung surgery, Fern's health deteriorated to the point where her doctors suggested that her children be called. Fern was rushed to a procedure room to put a bronchoscope into her lungs to see what was happening.

*NTM can affect any one of us . . . but for some unknown reason it affects more women than men.*

Fern's normal morning routine starts with pulmonary therapy to clear her airways. Then there is a sinus wash. With breakfast, Fern takes five different oral drugs and IV medicines. In addition, there are inhaled medicines. The total time from awakening to being able to leave the house is usually 4 hours.

## THE NEEDS OF NTM PATIENTS HAVE GONE UNMET—MORE CAN BE DONE NOW!

While tuberculosis is often known to appear in inner cities and immigrant populations, NTM knows no such boundaries. However, current epidemiologic data is not available. The latest data that we have from the Centers for Disease Control was collected in the 1980's and we urgently need newer data. Current data from the University of Toronto suggests that the prevalence may be six times higher than our older information. We have no reason to believe that Toronto is any different than Chicago, Miami or any other major U.S. city.

## PREPARED STATEMENT OF THE ONCOLOGY NURSING SOCIETY

## OVERVIEW

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding fiscal year 2008 funding for cancer and nursing related programs. ONS, the largest professional oncology group in the United States, composed of more than 35,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer.

This year more than 1,444,920 Americans will be diagnosed with cancer, and more than 565,000 will lose their battle with this terrible disease. Despite these grim statistics, significant gains in the War Against Cancer have been made through our Nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless, unless we can deliver them to all Americans in need. Moreover, a recent survey of ONS members found that the nursing shortage is having an adverse impact in oncology physician offices and hospital outpatient departments. Some respondents indicated that when a nurse leaves their practice, they are unable to hire a replacement due to the shortage—leaving them short-staffed and posing scheduling challenges for the practice and the patients.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates ongoing and significant Federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. The Society stands ready to work with policymakers at the local, State, and Federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the Nation's nursing workforce. We thank the subcommittee for its consideration of our fiscal year 2008 funding request detailed below.

## SECURING AND MAINTAINING AN ADEQUATE ONCOLOGY NURSING WORKFORCE

Oncology nurses are on the front lines in the provision of quality cancer care for individuals with cancer—administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing counseling to patients and family members, and engaging in myriad other activities on behalf of people with cancer and their families. Cancer is a complex, multifaceted chronic disease, and people with cancer require specialty-nursing interventions at every step of the cancer experience. People with cancer are best served by nurses specialized in oncology care, who are certified in that specialty. Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older.

As the overall number of nurses will drop precipitously in the coming years, we likely will experience a commensurate decrease in the number of nurses trained in the specialty of oncology. With an increasing number of people with cancer needing high-quality health care, coupled with an inadequate nursing workforce, our Nation could quickly face a cancer care crisis of serious proportion, with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the *New England Journal of Medicine* found that nursing shortages in hospitals are associated with a higher risk of complications—such as urinary tract infections and pneumonia, longer hospital stays, and even patient death. Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need, and patient health and well-being could suffer.

Further, of additional concern is that our Nation also will face a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of cancer research nurses, progress against cancer will take longer because

of scarce human resources coupled with the reality that some practices and cancer centers resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, we are concerned that our Nation may falter in its delivery and application of the benefits from our Federal investment in research.

ONS has joined with others in the nursing community in advocating \$200 million as the fiscal year 2008 funding level necessary to support implementation of the Nurse Reinvestment Act and the range of nursing workforce development programs housed at the U.S. Health Resources and Services Administration (HRSA). Enacted in 2002, the Nurse Reinvestment Act (Public Law 107-205) included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our Nation's nursing workforce. For example, in fiscal year 2006 HRSA received 4,222 applications for the Nurse Education Loan Repayment Program, but only had the funds to award 615 of those applications. Also, in fiscal year 2006 HRSA received 3,320 applications for the Nursing Scholarship Program, but only had funding to support 218 awards.

While a number of years ago one of the biggest factors associated with the shortage was a lack of interested and qualified applicants, due to the efforts of the nursing community and other interested stakeholders, the number of applicants is growing. As such, now one of the greatest factors contributing to the shortage is that nursing programs are turning away qualified applicants to entry-level baccalaureate programs, due to a shortage of nursing faculty. According to the American Association of Colleges of Nursing (AACN), U.S. nursing schools turned away 42,866 qualified applicants from baccalaureate and graduate nursing programs in 2006, due to insufficient number of faculty. The nurse faculty shortage is only expected to worsen with time, as half of the RN workforce is expected to reach retirement age with in the next 10 to 15 years. At the same time, significant numbers of faculty are expected to retire in the coming years, with insufficient numbers of candidates in the pipeline to take their places. If funded sufficiently, the components and programs of the Nurse Reinvestment Act will help address the multiple factors contributing to the nursing shortage.

The nursing community opposes the President's fiscal year 2008 budget proposal that decreases nursing workforce funding by \$44 million—a cut which eliminates all funding for advanced nursing education programs. With additional funding in fiscal year 2008, these important programs will have much-needed resources to address the multiple factors contributing to the nationwide nursing shortage, including the shortage of faculty—a principal factor contributing to the current shortage. Advanced nursing education programs play an integral role in supporting registered nurses interested in advancing in their practice and becoming faculty. As such, these programs must be adequately funded in the coming year.

ONS strongly urges Congress to provide HRSA with a minimum of \$200 million in fiscal year 2008 to ensure that the agency has the resources necessary to fund a higher rate of nursing scholarships and loan repayment applications and support other essential endeavors to sustain and boost our Nation's nursing workforce. Nurses—along with patients, family members, hospitals, and others—have joined together in calling upon Congress to provide this essential level of funding. One Voice Against Cancer (OVAC), a collaboration of more than 45 national nonprofit organizations representing millions of Americans, and the National Coalition for Cancer Research (NCCR), is a non-profit organization comprised of 26 national organizations, also advocate \$200 million for the Nurse Reinvestment Act in fiscal year 2008. ONS and its allies have serious concerns that without full funding, the Nurse Reinvestment Act will prove an empty promise, and the current and expected nursing shortage will worsen, and people will not have access to the quality care they need and deserve.

#### SUSTAIN AND SEIZE CANCER RESEARCH OPPORTUNITIES

Our Nation has benefited immensely from past Federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joined with the broader health community in advocating a 6.7 percent increase (\$32.831 billion) for NIH in fiscal year 2008. This will allow NIH to sustain and build on its research progress, resulting from the recent doubling of its budget, while avoiding the severe disruption to that progress that would result from a minimal increase. Cancer research is producing extraordinary breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for cancer patients. We

have seen extraordinary advances in cancer research, resulting from our national investment, which have produced effective prevention, early detection and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate \$5.131 billion to the National Cancer Institute (NCI) in fiscal year 2008 to support the battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery, to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest, such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses, such as cancer. ONS joins with others in the nursing community in advocating a fiscal year 2008 allocation of \$150 million for NINR.

#### BOOST OUR NATION'S INVESTMENT IN CANCER PREVENTION, EARLY DETECTION, AND AWARENESS

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our Nation does not invest sufficiently in these strategies. In 2005, the United States spend over \$2.0 trillion in healthcare—\$6,683 for every man, woman, and child; however we only allocate approximately 1 percent of that amount for population-based prevention efforts. The Nation must make significant and unprecedented Federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our Nation both for today and tomorrow.

As the Nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering, at the community level, what is learned from research. Therefore, ONS joins with our partners in the cancer community—including OVAC—in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the following fiscal year 2008 funding levels for the following CDC programs: \$250 million for the National Breast and Cervical Cancer Early Detection Program; \$65 million for the National Cancer Registries Program; \$25 million for the Colorectal Cancer Prevention and Control Initiative; \$50 million for the Comprehensive Cancer Control Initiative; \$25 million for the Prostate Cancer Control Initiative; \$5 million for the National Skin Cancer Prevention Education Program; \$10 million for the Ovarian Cancer Control Initiative; \$6 million for the Geraldine Ferraro Blood Cancer Program; \$145 million for the National Tobacco Control Program; and \$65 million for the Nutrition, Physical Activity, and Obesity Program.

#### CONCLUSION

ONS maintains a strong commitment to working with Members of Congress, other nursing societies, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow, and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face in the coming years. By providing the fiscal year 2008 funding levels detailed above, we believe the subcommittee will be taking the steps necessary to ensure that our Nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our Nation continues to make gains in our fight against cancer.

#### PREPARED STATEMENT OF PARENT PROJECT MUSCULAR DYSTROPHY

Chairman Harkin, ranking member Specter, and members of the committee: I want to thank you for this opportunity to submit testimony for the written record. My name is Pat Furlong, Co-Founder and CEO of Parent Project Muscular Dystrophy (PPMD) and the mother of two sons who battled Duchenne Muscular Dystrophy (DMD).

The past year has been historical for PPMD and the entire Duchenne and Becker Muscular Dystrophy (DBMD) Community. Right now, a drug that holds tremendous

potential for a percentage of patients suffering not only from Duchenne but from other neurological conditions, like Cystic Fibrosis, is in a Phase 2 clinical trial, and has received Fast Track designation from the Food and Drug Administration (FDA). We all waited anxiously and were relieved when PTC Therapeutics reported an increase presence of dystrophin in Duchenne patients involved in the initial Phase 2 clinical trial, and we are very hopeful more good news will be on the way. While the drug in question—PTC 124—is being developed by a private entity, I can say with confidence that we would not have reached this milestone if not for the significant investments made into DMD research by the National Institutes of Health (NIH).

It is for this very reason that NIH's investments into Duchenne and Becker research must not only be sustained but strengthened. All six Senator Paul Wellstone MD Research Centers of Excellence are in operation, and the Muscular Dystrophy Coordinating Committee (MDCC) is working to advance the government-wide MD agenda.

At the Centers for Disease Control and Prevention (CDC), active surveillance of Duchenne is taking place in five States, and we are making progress toward developing a DMD Patient Registry, replete with evidence-based care considerations. In addition, PPMD has partnered with the CDC on an education and outreach initiative that has produced materials that help explain Duchenne to children, enable doctors to offer accurate and timely diagnoses, and help parents ensure their children get the care they need and deserve. Through the pilot work in Mississippi, CDC and PPMD have taken concrete steps to educate people on the early warning signs of DBMD so patients get the earliest diagnosis possible.

I want to continue to urge the committee to support Federal funding for DBMD. Specifically, we are seeking:

- A \$2.5 million increase in MD activities at the CDC. Of this increase:
  - \$2.25 million should be dedicated to advancing efforts to develop and launch an International DBMD Patient Registry.
  - \$250,000 should be used to continue the successful joint CDC/PPMD Education & Outreach initiative, bringing the total for this project to \$1 million.
- Increased funding at the NIH to ensure the continued support of the six MD Centers of Excellence and other research initiatives focused on DBMD.

We are very well aware of the significant budgetary pressures—both internal and external—that you will be dealing with this year. That's why we believe we have put forth a reasonable request that seeks the funding necessary to sustain and advance the successes attained to date. Without such an investment, we fear we will lose ground and not receive the greatest return on investment possible.

On behalf of all families impacted by Duchenne and Becker MD, I thank you for your past support. I urge your panel and the entire Senate to continue to lead the way in providing critically needed dollars to support DBMD research at the NIH and patient support and related initiatives at the CDC.

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#### PREPARED STATEMENT OF THE PEOPLE FOR THE ETHICAL TREATMENT OF ANIMALS

Chairman Harkin, ranking member Specter, and members of the subcommittee: People for the Ethical Treatment of Animals (PETA) is the world's largest animal rights organization, with 1.6 million members and supporters. We greatly appreciate the opportunity to submit testimony regarding the fiscal year 2008 appropriations for the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM). The following national animal and health protection organizations support these comments: The American Anti-Vivisection Society, the Alternatives Research and Development Foundation, In Defense of Animals, and the Physicians Committee for Responsible Medicine.

As you are aware, Federal regulatory agencies require most chemicals and many other products to undergo tests that measure their toxicity levels. Unfortunately, most of these tests involve the suffering and death of animals. Other problems include agencies needlessly duplicating each other's tests, lack of innovation (e.g., relying on outdated and flawed test methods developed decades ago), and underutilization of scientific expertise outside of the U.S. Government (e.g., ignoring better methods used in other countries).

ICCVAM was created in 1997 to solve the three regulatory testing problems of animal suffering, wasteful duplication, and lack of innovation. It was made a permanent committee under the National Institute of Environmental Health Sciences in 2000.

Contrary to its ostensible purpose, however, ICCVAM has become a major obstacle to the adoption of more sophisticated and accurate test methods—in many cases,

methods that have been widely adopted by the rest of the industrialized world. Instead, ICCVAM is clinging to decades-old animal-poisoning tests that were never proven relevant to humans to begin with.

This causes two major problems. First, animals are being harmed needlessly when non-animal tests could be adopted instead. Second, public health is being undermined, as non-animal test methods have been demonstrated to be more accurate, more sensitive, and more protective of public health.<sup>1</sup>

In addition, test methods that use animals render our Federal agencies impotent in their efforts to regulate health and environmental hazards because the fact that these methods are not human-relevant leads to continual—and successful—court challenges on the part of industry.

ICCVAM's counterpart in Europe—the European Centre for the Validation of Alternative Methods (ECVAM)—has developed and validated a number of non-animal methods. Yet ICCVAM fails to even adopt the ECVAM-validated methods, becoming a bottleneck for the adoption of new methods in the United States.<sup>2</sup>

Worse, ICCVAM and its lead agency, the U.S. Environmental Protection Agency (EPA), have repeatedly and blatantly violated both the letter and the spirit of a major tenet of the Organization for Economic Cooperation and Development (OECD) Council Decision, of which the United States is a member. The OECD's 1981 Mutual Acceptance of Data in the Assessment of Chemicals provides that: "[D]ata generated in the testing of chemicals in an OECD Member country in accordance with OECD Test Guidelines and OECD Principles of Good Laboratory Practice shall be accepted in other Member countries for purposes of assessment and other uses relating to the protection of man and the environment."

Presented below are five specific recent examples:

1. *Skin Corrosion Testing*.—Two types of non-animal tests for skin corrosion, the Transcutaneous Electrical Resistance method (OECD 430) and human skin model studies (OECD 431), were successfully validated in partnership with ECVAM and endorsed by ECVAM's Scientific Advisory Committee (ESAC) in 1998, accepted by EU regulators in June 2000, and published as OECD Test Guidelines in April 2004. The OECD specifically accepts the tests as part of a strictly non-animal weight-of-evidence assessment of skin corrosion. Yet ICCVAM arbitrarily insists on confirmatory testing in rabbits of any negative results.

2. *Phototoxicity Testing*.—The cell-based 3T3 Neutral Red Uptake Phototoxicity Test is also ECVAM validated, ESAC endorsed, and codified in both EU regulations and as an OECD Test Guideline (OECD 432). However, the regulatory acceptance of this method in the United States remains uncertain.

3. *Ocular Testing*.—In 2005, ICCVAM reviewed several non-animal methods to replace the infamous Draize test, in which chemicals are dripped into the eyes of restrained (though not anesthetized) rabbits. These methods (which use actual animal eyes from slaughterhouses) have been accepted by some countries for more than a decade and are currently accepted throughout the EU through mutual acceptance of data. Nevertheless, ICCVAM has placed severe restrictions on their use.

4. *Acute toxicity testing*.—ICCVAM convened an international workshop in 2000 to discuss a non-animal (cell-based) method that had the potential to replace acute toxicity testing in animals. Acute toxicity testing, otherwise known as lethal poisoning, means taking a group of animals and forcing them to ingest or inhale a toxic

<sup>1</sup>For example, in 1971, scientists Weil and Scala examined the reliability of data from eye irritation tests—in which chemicals are dripped into rabbits' eyes—and concluded that, because of significant variability in test results from day to day and lab to lab, this test should not be used as a standard regulatory toxicity study (Weil CS and Scala RA. 1971. Toxicol. Appl. Pharmacol. 17: 276–360). In 1986, Freeberg and colleagues studied 281 cases of accidental human eye exposure to 14 household products and compared the outcome with the results of rabbit eye irritation tests. They found that the animal test failed to correctly predict the human eye response more than half (52 percent) of the time (Freeberg FE and others. 1986. J. Toxicol. Cutaneous & Ocular Toxicol. 5: 115–23). A few years later, Koch and colleagues at the U.S. Food and Drug Administration stated that there was no clear relationship between the rabbit eye response and the exposure of the human eye to chemicals or products and that the Draize test is "plagued" with a lack of reproducibility. (Koch WH. 1989. Cutaneous & Ocular Toxicol. 8: 17–22). The Multicenter Evaluation of In Vitro Cytotoxicity (MEIC) study examined the results of rat and mouse "lethal dose" toxicity studies—in which groups of animals are force-fed massive doses of a chemical until half of them convulse and die. The researchers found that rodent lethal dose tests were, at best, 65 percent predictive of acute toxicity in humans. By contrast, the MEIC study found that a "battery" of four non-animal tests using human cells was able to predict human toxicity with 84 percent accuracy (U.S. National Toxicology Program Interagency Centre for the Evaluation of Alternative Toxicological Methods. 2000 Sep. The Multicenter Evaluation of In Vitro Cytotoxicity (MEIC)—Summary).

<sup>2</sup>In its 10-year history, it has validated only one non-animal test method that originated in the United States.

substance in increasing amounts until half of the animals die. Although this method is almost universally recognized as an extremely cruel, crude, and imprecise test method that causes a tremendous amount of animal suffering, it remains the backbone of regulatory testing.

The workshop resulted in a report stating that the cell-based methods could be used immediately to reduce the numbers of animals killed and that, within 3 years—given the proper funding and effort—the method could be validated as a full replacement measure. It is now 7 years later, and ICCVAM has made no progress in implementing the cell-based methods even as a reduction measure and has cynically ignored its potential as a replacement measure.

*5. Pyrogenicity (Fever-Inducing) Testing.*—According to a March 2006 European Union press release, ECVAM “approved six new alternative testing methods that will reduce the need for certain drugs and chemicals to be tested on animals. The new tests use cell cultures rather than animals to establish the toxicity of cancer drugs and identify contaminated drugs.” Five of the tests replace the use of animals in pyrogenicity testing (for fever-inducing bacteria) for which hundreds of thousands of rabbits are currently used every year.

Despite the fact that these methods were less expensive than animal tests and that, as stated in the news release, “the tests approved . . . will not only reduce the number of animals needed for testing, but will also increase the accuracy of the tests, thereby making the products concerned safer” (emphasis added), ICCVAM’s peer review panel concluded that the methods were not valid as replacements for the rabbit test.

#### RECOMMENDATIONS

ICCVAM follows a double standard that sets ever-increasing hurdles for every non-animal method while accepting every animal test as the unquestioned gold standard. Companies are now attempting to circumvent ICCVAM, submitting their data from non-animal test methods directly to the relevant agency to consider, knowing that it is pointless to send a non-animal method to ICCVAM for review.

If Congress is to continue funding ICCVAM, the agency must be held accountable for its failures to date and be required to fulfill its mandate “to establish, wherever feasible, guidelines, recommendations, and regulations that promote the regulatory acceptance of new or revised scientifically valid toxicological tests that protect human and animal health and the environment while reducing, refining, or replacing animal tests and ensuring human safety and product effectiveness” (Public Law 106–545). At the very least, there should be reciprocity between ECVAM and ICCVAM and ICCVAM should be required to expeditiously adopt non-animal test methods developed and validated in Europe.

In its 2007 appropriations, Congress included report language that required ICCVAM to develop a 5-year plan to “identify areas of high priority for new and revised non-animal and alternative assays or batteries of those assays to create a path forward for the replacement, reduction and refinement of animal tests” by November 15, 2007 (House Report 109–15). In December 2006, PETA, The Humane Society of the United States, and other national animal protection organizations submitted extensive comments to NIEHS regarding essential components of this plan.

We respectfully request that the committee include the following report language for fiscal year 2008: “The committee understands that the American animal protection community has submitted recommendations for items to be included in ICCVAM’s 5-year plan to identify areas of high priority for new and revised non-animal and alternative assays or batteries of those assays to create a path forward for the replacement, reduction and refinement of animal tests. The committee requests that these recommendations be adopted by ICCVAM or, upon presentation of the plan to the committee by November 15, 2007, an explanation of any exclusions of the aforementioned recommendations be included.”

Thank you for your consideration of our request.

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#### PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA/ASSOCIATION OF POPULATION CENTERS

##### INTRODUCTION

Thank you, Chairman Harkin, ranking member Specter, and other distinguished members of the subcommittee, for this opportunity to express support for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS)—two agencies important to our organizations.

## BACKGROUND ON THE PAA/APC AND DEMOGRAPHIC RESEARCH

The PAA is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The APC is a similar organization comprised of over 30 universities and research groups that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. Major policy issues population researchers are studying include the demographic causes and consequences of population aging, trends in fertility, marriage, and divorce and their effects on the health and well being of children, and immigration and migration and how changes in these patterns affect the ethnic and cultural diversity of our population and the Nation's health and environment.

The NIH mission is to support research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, the NIH supports population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

## NATIONAL INSTITUTE ON AGING

According to the Census Bureau, by 2029, all of the baby boomers (those born between 1946 and 1964) will be age 65 years and over. As a result, the population age 65–74 years will increase from 6 percent to 10 percent of the total population between 2005 and 2030. This substantial growth in the older population is driving policymakers to consider dramatic changes in Federal entitlement programs, such as Medicare and Social Security, and other budgetary changes that could affect programs serving the elderly. Further, the macroeconomic and global impact of population aging on competitiveness in the world economy is becoming a bigger issue—as illustrated during the recent Global Summit on Aging sponsored by NIA and the State Department. To inform this debate, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, and health characteristics of the older population. The NIA Behavioral and Social Research (BSR) program is the primary source of Federal support for research on these topics.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers of Demography of Aging Program, the NIA BSR program also supports several large, accessible data surveys. Two such surveys, the National Long-Term Care Survey (NLTC) and the Health and Retirement Study (HRS) have become seminal sources of information to assess the health and socioeconomic status of older people in the United States.

By using NLTC data, investigators identified the declining rate of disability in older Americans first observed in the mid-1990s. In 2006, an analysis of the latest data found the prevalence of chronic disability among people 65 and older fell from 26.5 percent in 1982 to 19 percent in 2004/2005. The findings suggest that older Americans' health and function continue to improve at a critical time in the aging of the population. If it continues, this trend could have momentous impact on reducing the need for costly long-term care.

In 2006, NIA announced a 6-year renewal of the HRS. The HRS, now entering its 15th year, has tracked 27,000 people, and has provided data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. The Social Security Administration recognizes and funds the HRS as one of its "Research Partners" and posts the study on its home page to improve its availability to the public and policymakers. HRS is particularly valuable because its longitudinal design allows researchers: (1) the ability to immediately study the impact of important policy changes such as Medicare Part D; and (2) the opportunity to gain insight into future health-related policy issues that may be on the horizon, such as recent HRS data indicating an increase in pre-retirees self-reported rates of disability.

With additional support in fiscal year 2008, the NIA BSR program could fully fund its existing centers and support its ongoing surveys. Additional support would allow NIA to expand the centers' role in understanding the domestic macroeconomic as well as the global competitiveness impact of population aging and fully fund initiatives in fiscal year 2008 addressing financial challenges faced by older Americans.

NIA could also use additional resources to support individual investigator awards by precluding an 18 percent cut in competing awards, improving its funding pipeline, and sustaining training and research opportunities for new investigators.

#### NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN DEVELOPMENT

Since its establishment in 1968, the NICHD Center for Population Research has supported research on population processes and change. Today, this research is housed in the Center's Demographic and Behavioral Sciences Branch (DBSB). The Branch encompasses research in four broad areas: family and fertility, mortality and health, migration and population distribution, and population composition. In addition to funding research projects in these areas, DBSB also supports a highly regarded population research infrastructure program and a number of large database studies, including the Fragile Families and Child Well Being Study and National Longitudinal Study of Adolescent Health.

NICHD-funded demographic research has consistently provided critical scientific knowledge on issues of greatest consequence for American families: work-family conflicts, marriage and child bearing, childcare, and family and household behavior. However, in the realm of public health, demographic research is having an even larger impact, particularly on issues regarding adolescent and minority health. For example, in 2006, researchers with the National Longitudinal Study of Adolescent Health, reported findings illustrating that by the time they reach early adulthood (age 19–24), a large proportion of American youth have begun the poor practices contributing to three leading causes of preventable death in the United States: smoking, poor diet and physical inactivity, and alcohol abuse. This study is striking in that it found the health situation of young people—in terms of behavior, health conditions, and access to and use of care—deteriorates markedly between the teen and young adult years. The study reinforces the importance of educating young people about adopting healthy lifestyles after they leave high school and the parental home.

Understanding the role of marriage and stable families in the health and development of children is another major focus of the NICHD DBSB. Consistently, research has shown children raised in stable family environments have positive health and development outcomes. Therefore, NICHD supports research to elucidate factors that contribute to family formation and strong partnerships. Recent findings have identified factors that can destabilize relationships between new parents. These factors include serious health or developmental problems of the parents' child, lower earnings, less education, and a father who has other children with different mothers. A new study published in 2006 produced the first measures of multi-partnered fertility (having children by more than one partner) in U.S. urban areas. The study found that in 59 percent of unmarried couples with a new baby, at least one parent had a child from another relationship. Previous research demonstrates multi-partnered fertility has potentially serious implications for both child well-being and marriage promotion efforts because of the demands of existing commitments and relationships. Policymakers and community programs can use these findings to support unstable families and improve the health and well being of children.

With additional support in fiscal year 2008, NICHD could restore full funding to its large-scale surveys, which serve as a resource for researchers nationwide. Furthermore, the Institute could apply additional resources toward improving its funding pipeline, which has gone from the 20th percentile range in 2003 to the 15th percentile in January 2007. Additional support could be used to preclude cuts of 17 percent to 22 percent in applications approved for funding and to support and stabilize essential training and career development programs necessary to prepare the next generation of researchers.

#### NATIONAL CENTER FOR HEALTH STATISTICS

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the States to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey, National Health Interview Survey, and National Survey of Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the State of our Nation's health.

The President's fiscal year 2008 budget requests \$109.9 million in program funds for National Center for Health Statistics. This recommendation represents an increase of \$900,000 over the fiscal year 2007. Despite this modest increase, if enacted, the President's request would only allow NCHS to purchase 10 months of vital statistics data. Recently, PAA and APC joined 150 other organizations in sending a letter (<http://www.chsr.org/nchsletterhouse031507.pdf>) to the House and Senate Appropriations Committees expressing concern about this matter and asking that NCHS receive \$117 million in fiscal year 2008, an \$8 million increase over its fiscal year 2007 level. Without at least \$3 million in additional funding, the United States will become the first industrialized Nation unable to continuously collect birth, death, and other vital information. The full \$8 million increase is necessary to not only restore integrity and stability to the vital statistics program, but also to restore other important data collection and analysis initiatives and to modernize systems NCHS uses to manage and protect its data.

#### RECOMMENDATIONS

PAA and APC join the Ad Hoc Group for Medical Research in supporting an fiscal year 2008 appropriation of \$30.8 billion, a 6.7 percent increase over the fiscal year 2007 appropriation, for the NIH. We also urge the subcommittee to include language in the fiscal year 2008 bill allowing the National Children's Study to continue and to appropriate \$111 million for NCS in fiscal year 2008 through the NIH Office of the Director.

PAA and APC, as members of the Friends of NCHS, support a fiscal year 2008 appropriation of \$117 million, a 7 percent increase over the fiscal year 2007 appropriation, for the NCHS. This funding is needed to maintain the Nation's vital statistics system and to sustain and update the agency's major survey operations.

Thank you for considering our requests and for supporting Federal programs that benefit the field of demographic research.

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#### PREPARED STATEMENT OF PROJECT R&R: RELEASE AND RESTITUTION FOR CHIMPANZEES IN U.S. LABORATORIES

Project R&R, whose advisory board of chimpanzee experts includes 12 organizations with a combined membership of 500,000, respectfully submits testimony on our funding priority.

We request that Federal funding for breeding chimpanzees for research, or for projects that require breeding, be terminated. We do so for the following reasons:

- A "surplus" of chimpanzees has resulted from over-breeding in the 1980s for HIV/AIDS research and later findings that they are a poor HIV/AIDS model.<sup>1</sup>
- There are enough chimpanzees to address existing federally funded research.<sup>2</sup>
- As a result of the "surplus," the government funds a national sanctuary system.<sup>3</sup>
- The current population costs in excess of about \$11 million Federal per year.
- Breeding more chimpanzees increases taxpayers' financial burden.
- Expansion of the population compounds existing concerns about their quality of care.
- While there is a breeding moratorium, NIH still funds research projects requiring breeding.<sup>4</sup>
- The public is concerned about the use of chimpanzees in research.

#### BACKGROUND

Of an estimated 1,300 chimpanzees in laboratories in the United States today, approximately 850 are federally owned or supported. In the mid-1990s, the National Research Council (NRC) made recommendations to address the "surplus" that included a moratorium on breeding federally-owned or supported chimpanzees for at least 5 years<sup>5</sup> (implemented in 1995). The National Advisory Research Resources Council, which advises NCRR on funding activities, policies, and program, met on 09/15/05 and recommended that NCRR extend the moratorium to 12/07. The rec-

<sup>1</sup> National Research Council (1997) Chimpanzees in research: strategies for their ethical care, management and use. National Academies Press: Washington, D.C.

<sup>2</sup> Report of the Chimpanzee Management Plan Working Group to the National Advisory Research Resources Council; May 18, 2005.

<sup>3</sup> [http://www.ncrr.nih.gov/compmed/cm\\_chimp.asp](http://www.ncrr.nih.gov/compmed/cm_chimp.asp)

<sup>4</sup> Ibid.

<sup>5</sup> National Research Council (1997) Chimpanzees in research: strategies for their ethical care, management and use. National Academies Press: Washington, D.C.

ommendation was accepted<sup>6</sup>—reasons included the high costs associated with care and the fact that chimpanzees are a poor model for human HIV research.<sup>7 8</sup>

#### CIRCUMVENTING THE MORATORIUM

Despite the moratorium, NIH funds research projects requiring breeding. For example, the National Institute of Allergy and Infectious Diseases (NIAID) maintains a contract with the New Iberia Research Center (NIRC) to provide 10 to 12 infants annually for research. The 10 year contract entitled “Leasing of chimpanzees for the conduct of research” was allotted over \$22 million (some \$3.9 million plus has been spent since 2002).<sup>9</sup>

NIRC has also received \$5.47 million from 09/00 to 08/05 for a grant from NCRR to maintain 138 chimpanzees for breeding. NIH/NCRR spends more than \$1 million annually to maintain the NIRC breeding colony.<sup>10</sup> These grants result in \$9 million going to breeding-related activities at NIRC alone since 2000.

Such expenditures circumvent the intent of the breeding moratorium, compelling the need to prevent the growing financial burden of increasing numbers of chimpanzees, particularly since, by the government’s own admission, a “surplus” already exists.

#### COSTS FOR CHIMPANZEE MAINTENANCE

The cost of care for chimpanzees is a major concern, particularly with NIH’s tightening budget. In 1995, the Institute for Laboratory Animal Research (ILAR) published a study that projected the future costs of maintaining chimpanzees in U.S. research.<sup>11</sup> ILAR, a division of the National Academies of Science, functions as “an advisor to the Federal Government, the biomedical research community, and the public.”<sup>12</sup>

The ILAR study examined the per diem costs of the existing population of chimpanzees at six facilities. Taking into account a variety of factors such as longevity, distribution of sex, and complexity of care, it projected costs of maintaining the present colony over the next 60 years. To account for inflation, an annual 4 percent increase was incorporated, corresponding approximately to the Biomedical Research and Development Price Index.

The results of the study indicated that the lifetime cost of maintaining chimpanzees over the next 60 years—the approximate lifespan of chimpanzees in captivity—will exceed \$3.14 billion. The 1995 projection, however, was based on a population of 1,447 chimpanzees. The present population of federally owned or supported chimpanzees in 2007, due to factors such as the implementation of the partial breeding moratorium in 1995, the end of the Air Force’s use of chimpanzees and the close of the Coulston Foundation in 2002 (to which the majority of Air Force chimpanzees were sent), stands closer to 850. This represents approximately 59 percent of the 1,447 number used in ILAR’s projection. Thus we can estimate the Federal cost of the existing colony to be \$1.85 billion. The remainder of the original estimated \$3.14 billion figure will now be carried by the U.S. public which contributes to the private sanctuaries caring for formerly federally owned or supported chimpanzees (minus a slight decrease in this estimate due to mortality). Thus, the caring American public has been burdened with the ethical obligation of some estimated \$1.29 billion to care for chimpanzees from laboratories, without any further obligation for this care placed on the laboratories themselves and with none of these privately funded sanctuaries having, at this time, access to Federal dollars for their chimpanzee care. Given the American public’s deep and growing concern over the use of chimpanzees in research, the NIH’s history of breeding has created a hidden, even if self-assumed, “tax” for that faction of the public concerned about the humane and ethical treatment of chimpanzees from research for which NIH no longer assumes any financial responsibility.

<sup>6</sup>[http://www.ncrr.nih.gov/compmed/cm\\_chimp.asp](http://www.ncrr.nih.gov/compmed/cm_chimp.asp)

<sup>7</sup>Muchmore, E., (2001) Chimpanzee models for human disease and immunobiology, *Immunological Reviews*, 183, 86–93.

<sup>8</sup>Reynolds, V., (1995) Moral issues in relation to chimpanzee field studies and experiments, *Alternatives to Laboratory Animals*, 23, 621–625.

<sup>9</sup>Source: [http://dcis.hhs.gov/nih/nih\\_daily\\_active\\_web.html](http://dcis.hhs.gov/nih/nih_daily_active_web.html) (See contract No. 272022754)

<sup>10</sup><http://nirc.louisiana.edu/divisions/nihgrants.html>

<sup>11</sup>Dyke, B., Williams-Blangero, S. et al, 1995 “Future costs of chimpanzees in U.S. research institutions,” *ILAR Journal* V37(4) [http://dels.nas.edu/ilar\\_n/ilarjournal/37\\_4/37\\_4Future.shtml](http://dels.nas.edu/ilar_n/ilarjournal/37_4/37_4Future.shtml)

<sup>12</sup>Institute for Laboratory Animal Research, website at [http://dels.nas.edu/ilar\\_n/ilarhome/about.shtml](http://dels.nas.edu/ilar_n/ilarhome/about.shtml)

The ILAR projection also concluded that the 2006 annual costs would be approximately \$18.8 million. Adjusting this number by 59 percent results in \$11 million spent in 2006 alone to maintain chimpanzees for research.

It is important to note that \$11 million represents only a partial estimate of the entire Federal expenditure for chimpanzee research. The total population of U.S. chimpanzees available for research is estimated at 1,300. Approximately 500 of these chimpanzees are privately owned. Privately owned chimpanzees are also partially funded by Federal research dollars. Therefore, the 2006 estimate of annual expenditure actually exceeds \$11 million by an undetermined amount.

#### DELIVERY OF CARE

USDA inspection reports indicate that facilities housing chimpanzees for research are not adequately meeting basic housing needs. Inspection reports for the NIRC 2004 showed some chimpanzees being housed in less than the minimal space requirements. The facility was given 1 year to correct the non-compliance, which needed to be further extended as construction of new housing facilities was still not completed. NIRC was also cited 7 times during its 12/04 inspection for improperly sanitizing cages and living quarters, as well as for failing to provide adequate environment enhancement.

Inspection reports filed on the Southwest Foundation for Biomedical Research and the Yerkes Primate Facility, both National Primate Research Centers, also demonstrate multiple non-compliant items for failing to keep chimpanzee areas in well-maintained condition, and failing to maintain safe facilities free of dangers due to disrepair.

#### A POOR MODEL

It is widely agreed within the scientific community that chimpanzees are a poor model for HIV. Years of research demonstrated that HIV-infected chimpanzees do not develop AIDS. Similarly, while chimpanzees are used in current hepatitis C research, they do not model the course of the human disease. The decoding of the chimpanzee genome pointed out similarities as well as differences between humans and chimpanzees. Some of those greatest differences relate to the immune system.<sup>13</sup> Such differences question the validity of using chimpanzees in infectious disease research, further arguing the need to curb populations and costs.

#### ETHICAL CONCERNS

The U.S. public is concerned about the use of chimpanzees in research because of their intellectual, emotional and social similarities to humans. A 2005 poll conducted by the Humane Research Council revealed that 4 out of 5 (83 percent) of the U.S. public recognize chimpanzees as highly intelligent, social individuals who have an extensive capacity to communicate. A full 71 percent of Americans support the release of chimpanzees if they have been used in research for more than 10 years.<sup>14</sup> A 2001 poll conducted by Zogby International showed that 90 percent of Americans believe it is unacceptable to confine chimpanzees in government-approved cages.<sup>15</sup>

#### CONCLUSION

We respectfully request that the following language appear in the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee Report for fiscal year 2008:

“None of these funds shall be used for the breeding of chimpanzees or research projects that require the breeding of chimpanzees.”

We hope the committee will accommodate this modest request that will save the government substantial money, benefit chimpanzees, and allay some concerns and financial responsibilities of the public at large. Thank you for your consideration.

<sup>13</sup>The Chimpanzee Sequencing and Analysis Consortium/Mikkelsen, TS, et al., (1 September 2005) Initial sequence of the chimpanzee genome and comparison with the human genome, *Nature* 437, 69–87.

<sup>14</sup>U.S. Public Opinion of Chimpanzee Research, Support for a Ban, and Related Issues, Prepared for the New England Anti-Vivisection Society, by the Humane Research Council, 2005.

<sup>15</sup>Public Opinion Poll, Prepared for the Chimpanzee Collaboratory, by Zogby International, 2001.

## PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association (PHA).

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against a devastating disease. Pulmonary hypertension (PH) is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as: collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, or liver disease. PH does not discriminate based on race, gender, or age. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting. Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, making it impossible to receive a necessary heart or lung transplant.

PH is chronic and incurable with a poor survival rate. Fortunately, new treatments are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients managing the disorder for 20 years or longer.

Seventeen years ago, when three patients who were searching to end their own isolation founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland.

Today, PHA includes:

- Over 7,000 patients, family members, and medical professionals as members and an additional 28,000 supporters and friends.
- A network of over 140 patient support groups.
- An active and growing patient-to-patient telephone helpline.
- Three research programs that, through partnerships with the National Heart, Lung and Blood Institute and the American Thoracic Society, will have directed more than \$6 million toward PH research as of December, 2007.
- Numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension—published quarterly and distributed to all cardiologists, pulmonologists, and rheumatologists in the United States.
- A website dedicated to providing educational and support resources to patients, medical professionals, and the public that, over the past 9 years, has grown from receiving 600 visitors a month to 220,000 visitors a month.

## THE PULMONARY HYPERTENSION COMMUNITY

Mr. Chairman, I am privileged to serve as the president of the Pulmonary Hypertension Association and to interact daily with the patients and family members who are seeking to live their lives to the fullest in the face of this deadly, incurable disease. I would like to share with you the stories of two remarkable PH patients, Emily Stibbs and Charity Tillemann-Dick. Emily's and Charity's stories illustrate the impact of pulmonary hypertension not only on PH patients, but also on everyone who care about them.

When their daughter Emily was 5, Jack and Marcia Stibbs noticed that she could not keep up with the other children in the neighborhood. She seemed to lack the energy and strength to run and play. This condition worsened to the point where she would have to stop and rest after coming down the steps in the morning. Jack and Marcia noticed that when she was sitting on the bottom step in the morning, Emily's lips appeared to have a bluish color.

Jack and Marcia pressed for an answer to these problems for several months, and Emily was finally diagnosed with pulmonary hypertension. Doctors told the Stibbs family that Emily's probable remaining lifespan was 3 years.

Charity Tillemann-Dick's diagnosis with pulmonary hypertension took not months, but years. When Charity was in her late-teens, she had the opportunity to travel abroad and share her considerable talents as a budding opera singer at her grandfather's 75th birthday party in Budapest. Just before the performance, Charity collapsed, but the episode was explained away as a case of nerves.

Over the next few years, Charity continued to have occasional fainting spells as well as a progressive loss in energy. She was diagnosed as being everything from out of shape to anemic. When Charity finally received an accurate diagnosis, her PH had progressed further, and was therefore more difficult to treat, than it would have been if she had been diagnosed while the disease was in its early stages.

I am happy to report that, with treatment, Charity has continued to live a full and accomplished life, including performances at several world capitals. Emily, too, has outlived her 3-year prognosis by 7 years and continues to thrive. There is, however, no cure for pulmonary hypertension. Each day, courageous patients of every age lose their battle with PH.

Thanks to congressional action, and to advances in medical research largely supported by the NHLBI and other government agencies, Emily and Charity have an increased chance of living with their pulmonary hypertension for many more years. However, additional support is needed for research and related activities to continue to develop treatments that will extend the life expectancy of PH patients beyond the NIH estimate of 2.8 years after diagnosis.

#### FISCAL YEAR 2008 APPROPRIATIONS RECOMMENDATIONS

##### *National Heart, Lung and Blood Institute*

Mr. Chairman, PHA commends the National Heart, Lung and Blood Institute for its strong support of PH research, particularly through the creation of the Specialized Centers of Clinically Oriented Research in PH. We are very excited about the promise these Centers hold for the development of new treatments and for progress on the road to a cure. In addition, we applaud the NHLBI and the National Institutes of Health Office of Rare Diseases for their co-sponsorship a two-day scientific conference on pulmonary hypertension in December 2006. This important event provided an opportunity for leading PH researchers from the United States and abroad to discuss the State of the science in pulmonary hypertension and future research directions.

According to these leading researchers, we are on the verge of significant breakthroughs in our understanding of PH and the development of new and advanced treatments. Twelve years ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of five FDA approved therapies. Recognizing that we have made tremendous progress, we are also mindful that we are a long way from where we want to be in (1) the management of PH as a treatable chronic disease, and (2) a cure.

One crucial step in continuing the progress we have made in the treatment of PH is the creation of a pulmonary hypertension research network. Such a network would link leading researchers around the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the opportunities to collaborate on studies and to strengthen the interconnections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network.

In order to maintain the important momentum in pulmonary hypertension research that has developed over the past few years, and to create a much needed pulmonary hypertension research network, the Pulmonary Hypertension Association encourages the subcommittee to provide the National Institutes of Health, particularly the NHLBI, with a 6.7 percent increase in funding in fiscal year 2008.

##### *Centers for Disease Control and Prevention*

PHA applauds the subcommittee for its leadership over the years in encouraging the Centers for Disease Control and Prevention to initiate a Pulmonary Hypertension Education and Awareness Program. We know for a fact that Americans are dying due to a lack of awareness of PH, and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations. However Mr. Chairman, you don't have to rely solely on our word regarding the need for additional education and awareness activities. On November 11, 2005 the CDC released a long-awaited Morbidity and Mortality Report on pulmonary hypertension. In that report, the CDC states:

(1) "More research is needed concerning the cause, prevention, and treatment of pulmonary hypertension. Public health initiatives should include increasing physician awareness that early detection is needed to initiate prompt, effective disease

management. Additional epidemiologic initiatives also are needed to ascertain prevalence and incidence of various pulmonary hypertension disease entities." (Page 1, MMWR Surveillance Summary—Vol. 54 No. SS-5)

(2) "Prevention efforts, including broad based public health efforts to increase awareness of pulmonary hypertension and to foster appropriate diagnostic evaluation and timely treatment from health care providers, should be considered. The science base for the etiology, pathogenesis, and complications of pulmonary hypertension disease entities must be further investigated to improve prevention, treatment, and case management. Additional epidemiologic activities also are needed to ascertain the prevalence and incidence of various disease entities." (Page 7, MMWR Surveillance Summary—Vol. 54 No. SS-5)

Mr. Chairman, we are grateful to the CDC for their recent support of a DVD highlighting the proper diagnosis of PH. However, despite repeated encouragement from the subcommittee over the past 5 years, CDC has not taken any steps to establish an education and awareness program on PH. Therefore, we respectfully request that you provide \$250,000 in fiscal year 2008 for the establishment of a PH awareness initiative through the Pulmonary Hypertension Association.

*"Gift of Life" Donation Initiative at HRSA*

Mr. Chairman, PHA applauds the success of the Health Resources and Services Administration's "Gift of Life" Donation Initiative. This important program is working to increase organ donation rates across the country. Unfortunately, the only "treatment" option available to many late-stage PH patients is a lung, or heart and lung, transplantation. This grim reality is why PHA established "Bonnie's Gift Project."

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use "Bonnie's Gift" as a way to disseminate information about PH, transplantation, and the importance of organ donation, as well as organ donation cards, to our community.

PHA has had a very successful partnership with HRSA's "Gift of Life" Donation Program in recent years. Collectively, we have worked to increase organ donation rates and raise awareness about the need for PH patients to "early list" on transplantation waiting lists. For fiscal year 2008, PHA recommends an appropriation of \$25 million (an increase of \$2 million) for this important program.

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. We look forward to continuing to work with you and the subcommittee to improve the lives of pulmonary hypertension patients.

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PREPARED STATEMENT OF THE RYAN WHITE TITLE III MEDICAL PROVIDERS  
COALITION

The members of the Ryan White Title III Medical Providers Coalition are pleased to submit this statement for the record in strong support of a \$35 million increase to Title III (Part C) of the Ryan White Program for the fiscal year 2008 appropriations cycle. The Title III Coalition was founded to ensure that the voices of the HIV clinicians working on the frontlines of the AIDS epidemic in rural and urban communities across the Nation are represented in policy and program discussions that affect their ability to meet the medical needs of their patients with HIV/AIDS, including the national debate over the appropriate funding levels for the Ryan White CARE Act programs.

We formed our coalition in part to garner attention to the daily challenges we face in finding the necessary resources to ensure that our patients receive the comprehensive and complex medical care and services needed to sustain their health.

Title III of the Ryan White CARE Act provides grants to support outpatient medical services to HIV-positive individuals in underserved communities with no other source of care and treatment. Many Title III grants are in communities in which they are the only service providers accessible to un- and under-insured individuals. Our clinics use Title III funds to provide the range of services required to effectively manage and treat HIV disease, including physician care, medications, adherence counseling, laboratory testing, nutrition counseling and in some cases, mental health and substance abuse treatment.

Our clinical programs are seeing increasing numbers of patients with HIV/AIDS, with many of them presenting with serious, complex conditions in addition to HIV

disease, such as hepatitis C. We expect this trend to increase as States implement the Centers for Disease Control and Prevention's (CDC) recommendations for making HIV testing a more routine component of medical care. Additional resources for medical care, drug treatments and critical enabling services are essential if we are to continue providing state-of-the-art HIV care to our current patients and those newly identified with HIV disease.

As you finalize the funding recommendations for fiscal year 2008, we urge you to provide an urgently needed increase in funding for Title III (Part C) medical programs. After years of flat funding or decreases in grant awards, we estimate that the true need for these programs is an increase of at least \$83.3 million over fiscal year 2007. This amount is based on the estimated annual cost of delivering HIV-related outpatient care (\$2,414) multiplied by the current Title III caseload (191,229) plus the number of new patients that the Health Resources and Services Administration (HRSA) estimates will enter Title III programs in 2008 (36,333).

We appreciate the funding constraints that the committee is facing in determining fiscal year 2008 funding levels for a whole range of critical health programs. Therefore, at a minimum, we urge you to include a nominal \$35 million increase for Title III housed under the Ryan White Program, with a prioritization of increases within that \$35 million to current programs with the highest increases of patient burden. This proposed \$35 million increase, albeit inadequate to respond to the flat funding and growing caseloads that have characterized our programs for a number of years, will help us to continue to provide our patients with the essential medical care necessary to preserve health and prevent disease progression.

While Title III (Part C) funds are critical to our ability to meet the medical needs of low-income people with HIV/AIDS in our communities, the other Titles now referred to as Parts of the Ryan White CARE Act also are vital to supporting our HIV care systems. Many of us receive funding from multiple parts of the Ryan White CARE Act and use these resources to patch together a comprehensive system of care for our patients. We strongly support the Ryan White funding requests put forward by organizations representing other members of the HIV/AIDS community.

The HIV Medicine Association (HIVMA) and the American Academy of HIV Medicine (AAHIVM)—together representing most HIV clinical providers in the country—have joined forces to help assemble the Title III Coalition. Leadership of the Coalition includes providers from a wide range of settings, from New York City to New Orleans to Oakland, California.

If you have questions about the coalition, please contact Andrea Weddle at 703-299-1215 or Greg Smiley at 202-659-0699.

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#### PREPARED STATEMENT OF THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

##### SUMMARY OF THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY'S FISCAL YEAR 2008 RECOMMENDATIONS

A 6.7 percent increase for all of the National Institutes of Health (NIH) and for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

Establish a skin disease clinical trials network that will collect baseline data for specific orphan diseases and facilitate the exchange of scientific data across disciplines and institutes.

Encourage NIAMS to develop collaborative funding mechanisms with other NIH institutes and private foundations that leverage skin biology studies as a developmental model that will serve for the advancement of research across a multitude of diseases and specialties.

Encourage NIAMS to sponsor studies that capture general and skin-disease specific measures in order to generate incidence, prevalence and quality of life data attributable to skin diseases.

Increase the number of training awards through the NIH designed to facilitate the entry of more individuals into careers in skin disease research.

##### BACKGROUND

The Society for Investigative Dermatology (SID) was founded in 1938. Its 2,000 members represent over 40 countries worldwide, including scientists and physician researchers working in universities, hospitals and industry.

Along with our colleagues from the American Academy of Dermatology Association (AADA), members of the SID are dedicated to the advancement and promotion of the sciences relevant to skin health and disease through education, advocacy and the scholarly exchange of scientific information.

This collective commitment to research is evidenced in the scientific journal published by the SID, the Journal of Investigative Dermatology (JID). The JID is a catalyst for the exchange of scientific information pertaining to the 3,000 skin diseases that afflict nearly 80 million Americans annually.

The purpose of submitting testimony is to increase awareness of the need for more skin research, based on the burden attributable to skin disease. It will also highlight some of the advancements that past support has enabled.

We join with the Ad Hoc Group for Medical Research Funding in asking for a 6.7 percent increase for the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

#### BURDEN OF SKIN DISEASE

Prior bill report language directed NIAMS to "consider supporting the development of new tools to measure the burden of skin diseases, and the training of researchers in this important area". There are only a handful of researchers working on NIH-sponsored research that will provide such measures.

Skin disease impacts our citizens more than previously estimated. A report released in 2004 by the SID and the AADA, "The Burden of Skin Disease", compiled data from only 21 of the known 3,000 skin diseases and disorders. The estimated economic costs to society each year from those 21 diseases totaled nearly \$39 billion.

The true impact extends far beyond mere economics. These patients encounter discomfort and pain, physical disfigurement, disability, dependency and death. Skin conditions affect an individual's ability to interact with others and compromise the self-confidence of those inflicted.

One of the most striking findings in the study was the lack of general and skin-disease specific measures that are needed to generate data surrounding the incidence, prevalence, economic burden, quality of life and handicaps attributable to these diseases.

We ask the committee to devote the resources needed to develop components of national health surveys that capture dermatological data above and beyond skin cancer incidence and prevalence.

#### RESEARCH ADVANCES

Skin is the body's largest organ and serves as the primary barrier to external pathogens and toxins. Researchers at the NIH campus and institutions around the country are working diligently to define how the skin functions to protect us, how this fails in disease, and how compromised functions in disease can be restored.

Cell biology allows scientists to understand the life cycle of skin and hair-producing cells and identify the causes of disease, leading to better treatments and preventative measures. Advances in wound healing and skin ulcers are helping the elderly, veterans and patients with diabetes and burns. Lasers continue to provide less invasive options for patients requiring surgery.

Fundamental discoveries resulting from skin biology and translational research have yielded advances that are broadly applicable to human development and disease. Continued investment is required to fully capitalize on these ground-breaking advances.

Important new research findings include the following:

- The genes responsible for skin cancer and inherited skin diseases have been identified, making targeted therapy possible.
- The molecular mechanisms of auto-immune and inflammatory skin diseases are better understood, allowing for the use of focused, selective immunosuppressive therapy with greater safety and efficacy.
- Oral medications to treat and prevent viral and fungal diseases have become available.
- Lasers have made possible the removal of disfiguring skin malformations.
- Modern phototherapy and photochemotherapy allow for more effective treatment of inflammatory skin disease, lymphoma, depigmenting disorders and auto-immune diseases.
- Retinoids and sunscreens have reduced the risk of skin cancer in the elderly, in transplant patients, and in other populations.
- Painless transdermal drug delivery has become available.

Recent developments in the areas of clinical epidemiology, biostatistics, economics and the quantitative social sciences have begun to provide objective evaluation measures, although additional and improved measures are still desperately needed. These measures will help to identify effective interventions and allow us to better quantify contributions to the quality of life and health of Americans.

We ask the NIH to work to identify additional biomarkers in order to better understand skin disease pathways and interaction with other diseases and environmental factors.

#### TRANSLATING DISCOVERY TO TREATMENTS FOR AMERICANS

The goal of skin disease research is to improve the quality of life for the one in three Americans that suffer from skin disease. That goal is embedded in the collective missions of the SID and the intramural and extramural scientists funded through the skin portfolios of many of the 27 institutes and centers of the NIH.

Medical research organizations such as the SID are the direct recipients of the awards made possible through the rigorous peer-reviewed grant system in place at the NIH. The ultimate beneficiaries are the nearly 80 million Americans that stand to benefit from the discoveries resulting from research grants.

Inadequate levels of Federal funding have forced the institute administrators to reduce certain types of the available funding mechanisms currently in place at the NIH, to decrease success rates, to increase administrative cost reductions, to consider decreasing the number of awards and to cut award levels in existing programs.

Unfortunately, this reality impairs the ability of hypothesis-driven research to drive the research system. Adequate funding levels will allow the peer-review system to work at full potential, leading to findings that translate into better care for those suffering from debilitating diseases. Without sufficient funding provided specifically for skin research, nearly one third of the Nation would be denied any hope for a better quality of life.

We are grateful for the past support that has been given to the NIH and ask you to look for innovative ways to avoid flat or decreased funding levels for the institutes that are charged with improving the health of all Americans.

#### PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

Mr. Chairman and members of the committee: The Society for Maternal-Fetal Medicine is pleased to have the opportunity to testify on behalf of the fiscal year 2008 budget for the National Institute of Child Health and Human Development and to extend to the committee our appreciation for the support you have provided over the years to the National Institutes of Health, and in particular the National Institute of Child Health and Human Development.

Established in 1977, the Society for Maternal-Fetal Medicine (SMFM) is a not-for-profit organization of over 2,000 members that are dedicated to improving perinatal care through research and education. Maternal-fetal medicine doctors have advanced knowledge of the obstetrical, medical, genetic and surgical complications of pregnancy and their effects on both the mother and fetus. The many advances in research have allowed the maternal-fetal medicine physician to provide the direct care needed to treat the special problems that high risk mothers and fetuses face.

Having a high-risk pregnancy means that a woman has a greater chance of complications because of conditions in her pregnancy, her own medical status or lifestyle, or due to external factors. Many times, complications are unexpected and may occur without warning. Other times, there are certain risk factors that make problems more likely. For example:

—*Preterm Birth.*—Preterm birth is defined as births occurring before 37 weeks of gestation. Prematurity is the leading cause of newborn death and an estimated 20 percent of infants who survive suffer long term consequences, including cerebral palsy, mental retardation, and developmental delays that affect the child's ability to do well in school. The rate of preterm births has increased 30 percent since 1981 and in 2004, 508,000 babies were born prematurely.

Due to the growing problem of preterm birth, expanded research is needed on the underlying causes of preterm delivery and the development of treatments for the prevention of premature birth. SMFM recommends that the NIH Common Fund be utilized as a mechanism to fund research on preterm birth. As reported in the 2006 Institute of Medicine report, "Preterm Birth: Causes, Consequences, and Prevention," a multidisciplinary research approach is needed to better understand premature birth.

—*Adverse Pregnancy Outcome in Nulliparous Women.*—A recent national study showed that the rate of preterm births among first pregnancies has increased over 50 percent over the past decade and comprise about 40 percent of pregnant women in the United States. The rate of adverse pregnancy outcomes is unpredictable and substantial. For example, at least 12 percent of these women will have a preterm delivery, with associated high rate of neonatal mortality and long term morbidity. The data also revealed that women in their first pregnancy

are at highest risk for developing pre-eclampsia, which puts them at risk for devastating maternal complications, fetal death, and preterm delivery. Once one of these adverse outcomes has occurred, these women are considered at increased risk in their next pregnancy. In addition, the study also showed a racial disparity with Black women at a two-fold higher risk than white women. The prediction and prevention of the first adverse outcome is problematic and there is a paucity of research on the etiology, mechanism, and potential preventive interventions for poor pregnancy outcomes in this population.

SMFM recommends that NICHD launch an intensive research study of first pregnancy women in order to fill the major gap in our knowledge for the prevention of these complications.

—*Outcomes of Assisted Reproductive Technology.*—The increasing use of assisted reproductive technology (ART) over the past two decades has allowed thousands of infertile couples to have children, currently accounting for 1.1 percent of the total U.S. births and 17.1 percent of U.S. multiple births (CDC, 2002). ART includes all fertility treatments in which both eggs and sperm are handled in vitro such as in vitro fertilization with transcervical embryo transfer, gamete and zygote intrafallopian transfer, frozen-embryo transfer, and donor embryo transfer. Between 1996 and 2002, the number of births after ART treatment in the United States increased by 120 percent. ART is a significant contributor to preterm delivery and associated risks of prematurity. There is recent evidence of higher rates of adverse pregnancy outcomes even in singleton pregnancies associated with ART including increased preterm and term low birth weight, very low birth weight, preterm delivery, fetal growth restriction, genetic disorders, and congenital anomalies. The risks of birth defects are two times higher in ART babies as compared with naturally conceived singleton babies.

There is a lack of research on the mechanism for this increase in the adverse pregnancy outcomes. There is also insufficient research to date concerning the prevalence of adult chronic conditions, learning and behavioral disorders, and other reproductive effects in ART babies. Given the data for more proximal outcomes, these long-term outcomes should also receive further study. Preliminary results indicate that there may be an increase incidence of autism in ART offspring.

SMFM recommends a multi-center observational prospective cohort study on ART be conducted that would emphasize pregnancy outcomes—short- and long-term effects on children—to determine if the increase in adverse pregnancy outcomes are specifically related to the ART procedures versus underlying factors within the couple, such as coexisting maternal disease, the causes of infertility, or differences in behavioral risk and examine each step in the ART process to understand the mechanism for increased adverse pregnancy outcomes.

The National Institute of Child Health and Human Development is to be congratulated for its efforts to advance our understanding of the magnitude of complications related to pregnancy and for its efforts to sustain the investment in research during this time of tight budget constraints.

—A recent study found that molecules in blood can foretell the development of preeclampsia, a life-threatening complication of pregnancy. This finding appears to be an important step in developing a cure for preeclampsia.

—Researchers have developed an experimental vaccine that reduces stillbirths among rodents born to mothers infected with cytomegalovirus (CMV)—a common virus that can also cause mental retardation and hearing loss in newborn children who were infected in early fetal life.

According to NIH Director Elias Zerhouni, “medical science has dramatically improved our ability to help very small and premature babies survive. But as the rate of premature births continue to rise, it is even more critical that we develop ways to prevent many of the complications related to prematurity so that these children can lead healthy, robust lives.”

#### RECOMMENDATIONS

SMFM urges this committee to continue to provide NICHD with sufficient funds so that the Institute can continue to make momentous advances in research that will result in improved health of mothers and children. We recommend:

—Fund NIH at the amount authorized for fiscal year 2008 in the NIH Reform Act of 2006.

—Provide \$1,448,544,000 for NICHD in fiscal year 2008.

—Full funding for the—

—Maternal Fetal Medicine Units Network so that it can continue to address issues pertaining to preterm births and low birth-weight deliveries.

- Genomics and Proteomics Network for Premature Birth, which will hasten a better understanding behind the pathophysiology of premature birth, discover novel diagnostic biomarkers and ultimately aid in formulating more effective interventional strategies to prevent premature birth.
  - Stillbirth Collaborative Research Network which is addressing stillbirth, a major public health issue with morbidity equality to that of all infant deaths.
- Thank you for allowing SMFM the opportunity to present our views to the committee.

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## PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

### INTRODUCTION

Mr. Chairman and members of the subcommittee, I am David Van Essen, PhD, president of the Society for Neuroscience (SfN) and the Edison Professor of Neurobiology and Head of the Department of Anatomy and Neurobiology at Washington University in St. Louis, MO. I also currently serve on the Advisory Council of the National Institute of Neurological Disorders and Stroke.

I am writing in my capacity as SfN president to request your support for biomedical research funding at the National Institutes of Health (NIH). During the past several decades, NIH funding has allowed the neuroscience community to improve health outcomes and the quality of life for millions of Americans.

### WHAT IS THE SOCIETY FOR NEUROSCIENCE?

SfN is a nonprofit membership organization made up of more than 36,500 basic scientists and physicians who study the brain and nervous system. Recognizing the tremendous potential for the study of the brain and nervous system as a separate field, the Society was formed in 1969. Since then, SfN has grown from 500 members to the world's largest organization of scientists devoted to the study of the brain. Today, there are more than 300 training programs in neuroscience in the United States alone.

Neuroscience includes the study of how the brain senses and perceives our world, how it learns and remembers, how it controls our movements and our emotions, how it regulates sleep and responds to stress, how it develops and ages, and how it malfunctions in countless neurological and psychological disorders. Neuroscience also involves studies of the molecules, cells and genes responsible for proper nervous system functioning.

SfN's primary goal is to advance the understanding of the brain and the nervous system in health and disease. As such, each fall, some 30,000 scientists from around the world gather to exchange ideas about cutting-edge research on the brain, spinal cord, and nervous system at the Society's annual meeting.

### THANK YOU FOR PAST SUPPORT

SfN would like to thank the members of this subcommittee for their past support, which resulted in the doubling of NIH budget between 1998 and 2003. In particular, we are extremely grateful that the fiscal year 2007 Joint Resolution included an additional \$620 million for NIH above the fiscal year 2006 funding level. This additional money will allow NIH to award an extra 500 research grants. It will also create a new \$40 million program to support innovative, outside-the-box research, as well as \$91 million for grants to first-time investigators.

### MY RESEARCH

Currently, my research focuses on the structure and function of the cerebral cortex in humans and nonhuman primates. The cerebral cortex is the dominant structure of the human brain. It plays a key role in mediating our perceptions of the world around us, our cognitive capabilities, our emotions, and the control of our movements. It is highly variable from one individual to the next and is largely responsible for our unique personalities. Many neurological and psychiatric disorders arise from abnormalities of the cerebral cortex that are caused by hereditary or developmental factors or by injuries to cortical gray matter or to the underlying white matter.

My laboratory has developed novel methods of computerized brain mapping that allow accurate mapping of the complex convolutions of the cerebral cortex and accurate comparisons between individuals. Using these methods, we have worked with many collaborators to characterize patterns of cortical development in prematurely born human infants and abnormalities of cortical folding in specific disorders, in-

cluding William's Syndrome, autism, and schizophrenia. We have compared humans and in macaque monkeys (an intensively studied nonhuman primate), in order to better understand the differences that reflect the dramatic evolution of the human brain as well as the similarities that reflect common principles of cortical structure and function. In addition, my laboratory is active in the newly emerging field of neuroinformatics; we have developed a database and related tools to help neuroscientists communicate their discoveries and share their experimental data more effectively, thereby accelerating the pace of discovery and the efficiency of the neuroscience research enterprise.

#### NIH-FUNDED RESEARCH SUCCESSES

Today, scientists have a greatly improved understanding of how the brain functions thanks to NIH-funded research. To illustrate this progress SfN has created a 36-part series, called Brain Research Success Stories, which discuss some of the progress that has resulted from Federal funding for biomedical research. The following are just a few areas where our research efforts have helped the American public:

(1) *Down Syndrome*.—About one out of every 800 babies is born with Down Syndrome (DS) a disorder that includes a combination of birth defects such as mental retardation, certain physical distinctions, and an increased risk of several medical conditions, including heart problems, intestinal malformations, and visual or hearing impairments.

DS often results in high medical and non-medical costs, such as special education, rehabilitation, and other services. Data from 1992 suggests that each new case of DS costs over \$450,000 each year.

NIH-funded research has led to the development of several medical tests that help identify whether a pregnant woman is carrying a baby with DS. These tests allow parents to prepare themselves mentally and financially, and give them time to secure intervention programs that can aid in their child's development.

Once a child is born, research shows that early intervention programs can benefit those with DS. For example, adolescents with DS who received intervention programs early in life had significantly higher scores on measures of intellectual functioning than a comparison group. Such improvements might help those with DS live more independently and maintain a job later in life.

(2) *Schizophrenia*.—This disease affects nearly 2 million Americans, and costs the United States over \$32 billion a year in lost productivity and treatment. This devastating brain disorder torments sufferers with hallucinations, delusions, disordered thinking patterns, and memory deficits.

In the past, many individuals with schizophrenia became permanently lost to the social withdrawal and other behavioral problems characteristic of this disease, which is rooted in abnormal biology of the brain. However, thanks to NIH-funded research, new treatments, such as clozapine, have been developed.

Today's medications have fewer side effects and are more effective than older treatments. They help to quell the psychotic symptoms of schizophrenia, allowing patients to function more effectively in society. The medications also appear to cut the financial burden of the disease, decreasing hospital stays and treatment costs.

(3) *Amyotrophic Lateral Sclerosis*.—Each year, 5,000 Americans are diagnosed with the progressive neurological disease, called amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. The cost of treating these people is \$300 million annually. ALS takes a quick toll on sufferers. Affected individuals may first notice muscle weakness, twitching, or cramping. The disease then progressively disables a person's ability to walk, talk, or swallow and, ultimately, to breathe. Many spend their last days completely unable to move, while their minds remain alert. ALS usually occurs in midlife and kills patients within 3 to 5 years of occurrence.

Government-funded ALS research produced a number of important findings in the early 1990s. First, researchers were able to start pinning down how the disease progresses by identifying the role of the potentially toxic amino acid glutamate. ALS sufferers tend to have higher levels of this chemical messenger in certain parts of their body, and scientists have noted that nerve cells exposed to high concentrations of glutamate over a long time start to die.

Researchers were able to use this basic research discovery to develop riluzole, an anti-glutamate drug that extends the lives of ALS patients. The first drug shown to change the course of ALS, it was approved by the Food and Drug Administration in 1995. In 1993, researchers supported by NIH identified a genetic component of the hereditary form of ALS and subsequently developed an animal model for ALS. This has allowed researchers to advance their study of the disease and to test dozens of potential treatments.

## RESEARCH IMPROVES HEALTH AND FUELS THE ECONOMY

Diseases of the nervous system pose an enormous public health and economic challenge, as they directly affect nearly one in three Americans at some point in life, and indirectly affect nearly everyone by the adverse impact on family and friends. Understanding how the brain and nervous system develops, works, and ages—in health and disease—is the goal of neuroscientists. Improved health outcomes and positive economic data support the assertion that biomedical research is needed today to improve public health and save money tomorrow. Research drives innovation and productivity, creates jobs, and fuels local and regional economies.

Not only does research save lives and fuel today's economy, it is also a wise investment in the future. For example, 5 million Americans suffer from Alzheimer's disease today, and the cost of caring for these people is staggering. Medicare expenditures are \$91 billion each year, and the cost to American businesses exceeds \$60 billion annually, including lost productivity of employees who are caregivers. As the baby boom generation ages and the cost of medical services increases, these figures will only grow. Treatments that could delay the onset and progression of the disease by 5 years could save \$50 billion in healthcare costs each year. Research funded by the NIH is critical for the development of such treatments. The cost of investing in NIH today is minor compared to both current and future healthcare costs.

## PRESIDENT'S BUDGET NEGATIVELY IMPACTS RESEARCH

SfN is disappointed that the Bush administration's fiscal year 2008 budget proposes to cut funding for the National Institutes of Health by more than a half billion dollars in fiscal year 2008.

Mr. Chairman, inflation has eaten into the NIH budget. The NIH now projects the Biomedical Research and Development Price Index (BRDPI) may increase by 3.7 percent for both fiscal year 2007 and fiscal year 2008; 3.6 percent for fiscal year 2009 and 2010; and 3.5 percent for fiscal year 2011 and fiscal year 2012. Unfortunately, the President's budget for NIH did not factor in the increases in biomedical research inflation.

Several years of funding for NIH that are well below inflation rates has made efficient research planning difficult, led to a slower rate of research progress, and delayed the payoffs from recent scientific advances. As you know, basic research projects take years from conception to completion. Many excellent research projects have been curtailed in recent years because of the low percent age of grants receiving funding. In order to have maximum impact in our search to understand and treat disorders, we need a consistent, adequate level of funding. Without such a strategy, the Federal Government runs the great risk of spending many more dollars later on in medical costs and time lost from work. In recent months, we have been speaking with leaders in the biotechnology and pharmaceutical industries, who depend on NIH-funded discoveries a vital prelude to and driver of their product development efforts. They agree that rather than considering funding for NIH an expense, it should be considered an investment to address problems our country will face tomorrow.

We need a funding stream that keeps pace with the potential for advances that will help people lead healthier, more productive lives. NIH became the premier biomedical research institution it is today only through sustained support from congressional leaders, like you, to invest in the best facilities, research, and projects selected through a non-political, rigorous, and competitive peer review system that is envied and is now being emulated around the world.

## FISCAL YEAR 2008 BUDGET REQUEST

NIH funded research saves lives and fuels the U.S. economy. Further, sustained investment in the NIH will lead to more effective treatments that will lessen future healthcare costs for the baby boom generation. Unfortunately, inflation and relatively flat funding have eaten into the NIH budget.

The Society for Neuroscience supports a 6.7 percent increase in funding for NIH per year for each of the next 3 fiscal years. This increase translates to an additional \$1.9 billion for NIH in fiscal years 2008, 2009, and 2010.

This sustained increase is necessary to make-up for lost purchasing power that has occurred in the past 3 years. In addition, increased funding will help NIH to achieve future research goals by, among other things, helping to ensure that our best and brightest young people will enter the field and continue to make neuroscience research advances that are so vital to achieving a healthier Nation and a robust economy.

Mr. Chairman, thank you for the opportunity to submit testimony before this subcommittee.

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PREPARED STATEMENT OF THE SOCIETY OF TEACHERS OF FAMILY MEDICINE; ASSOCIATION OF DEPARTMENTS OF FAMILY MEDICINE; ASSOCIATION OF FAMILY MEDICINE RESIDENCY DIRECTORS; AND NORTH AMERICAN PRIMARY CARE RESEARCH GROUP

HEALTH PROFESSIONS: PRIMARY CARE MEDICINE AND DENTISTRY (TITLE VII, SECTION 747)

We request that this committee fund the Primary Care Medicine and Dentistry Cluster (section 747 of Title VII) at no less than the fiscal year 2005 level of \$88.8 million. This cluster received \$48.9 million in the final fiscal year 2007 spending resolution, but the President's budget for fiscal year 2008 eliminates Title VII Health Professions Grants, except for \$10 million in Scholarships for Disadvantaged Students.

In fiscal year 2006, funding for the health professions programs was cut dramatically. The primary care medicine and dentistry cluster was cut by 54 percent. The effect was to prevent any new competitive grant applications for that year and to cut the funding of those grants that were continuing in their second or third year. This year, instead of providing the committee with national studies regarding the effectiveness of these programs, we would like to put a human face to the impact of the cuts in fiscal year 2006. Below are anecdotes received from across the country showing, in their own words, how the institutions that apply for and receive these grants were affected by the loss of almost \$50 million of Federal funding.

*University of Iowa, Department of Family Medicine.*—At Iowa, we furloughed 5 individuals (that means let them go) related to our educational and academic mission. We have had to shift funding from other core areas and reduce or eliminate programs that focused mostly on primary care fellowship training, academic development, preceptor education development and travel support to rural Iowa communities. Our department had consistently received about \$800,000 to \$1,000,000 a year over the last 30 years and now we have none of that support. Paul James, MD, Chair, Department of Family Medicine

*University of Buffalo, Department of Family Medicine.*—Here at the University at Buffalo we have laid off a PhD Clinical Psychologist who had been with the Department for 9 years. He participated actively in our clerkship training and in our residency training. He taught both students and residents about helping patients change behaviors (quit smoking, etc) and trained residents in dealing with difficult or non-compliant patients as well as the more difficult and time consuming issues of long term family therapy. We also laid off a master degree medical education specialist. We are the only medical school department to have had a person like this on our staff but she assured that our exams measured the goals of our training and our curriculum taught to these goals. Tom Rosenthal, MD, Chair, Department of Family Medicine

*Tufts University, Division of Family Medicine.*—At Tufts, we hired three minority faculty to increase the diversity of our faculty and now we will have to let go of one of them and reduce the time significantly of the other two because of our loss of funding. We also have an educational program that teaches students how to interview patients who do not speak English through a medical interpreter. We will have to cut that program as well. Wayne Altman, MD FAAFP

*Montana Family Medicine Residency.*—Many of our successes, including the integration of a top notch primary care mental illness management and collaborative program and a Northern Plains Indian cultural education program, have been possible only through Title VII funding. Our growth as a rather isolated residency—the only one in the State in any specialty, and remote from our affiliated University—is dependent on grant programs that are specifically designed for family medicine resident training . . . Geographically isolated programs like ours in Montana and also Alaska, and Wyoming also need to develop their own infrastructure . . . Roxanne Fahrenwald MD, Director, Montana Family Medicine Residency.

*University of North Carolina, Department of Family Practice.*—We cut one of our objectives [in our continuation grant] because there was not enough money to pay for it. It was a session on health disparities that we intended to introduce to all of our clerkship students, and then have them look at the issue during their clinical experience in a practice. The money we had intended to pay for the faculty involved was eliminated and she had to make it up from patient care time. Bob Gwyther, MD

*Thomas Jefferson University, Department of Family and Community Medicine.*— . . . Predoctoral—Unable to expand our rural Physician Shortage Area Program (which has successfully increased the rural physician supply in Pennsylvania) to the State of Delaware; and unable to develop and implement new curricula focusing on vulnerable populations in the areas of health literacy, oral health, domestic violence, and medical professionalism. Howard Rabinowitz, MD [This entry was extracted from a longer list of six program areas that were deeply affected by these cuts]

*WWAMI (a Partnership Between the University of Washington School of Medicine and the States of Wyoming, Alaska, Montana, and Idaho).*—We have had some programmatic impacts on the faculty development fellowship program across the five WWAMI States. For us the impact of the funding cut was having to eliminate the support for a second year of training that would have exported fellows' projects to other programs and nationally. This was the opportunity to make use of what they had gained in the fellowship year in a way that solidified their learning and spread that learning to others. These changes meant the discipline, the region, and BHP [Bureau of Health Professions] didn't get to reap the benefit of these physicians' activities. *In a sense they lost the public good beyond the training of the individual faculty.* [emphasis added] Finally we lost the chance to see if that new model worked. Ardis Davis, MSW

#### THE AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

We request funding of \$350 million for AHRQ in fiscal year 2008. This is an increase of \$31 million over fiscal year 2007, and \$20 million more than the President's fiscal year 2008 budget request. It should be noted however that a much larger investment should be made, as recommended by The Institute of Medicine's report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001). It recommended \$1 billion a year for AHRQ to "develop strategies, goals, and actions plans for achieving substantial improvements in quality in the next 5 years . . ." The report looked at redesigning health care delivery in the United States. AHRQ is a linchpin in retooling the American health care system.

For the last several years, funding for AHRQ has remained relatively stagnant, while it's portfolio of work has increased dramatically. Our researchers are finding that investigator-initiated grants are very difficult to obtain. In their own words, this is the status of AHRQ funding:

*Brown University, Department of Family Medicine.*—AHRQ funds so little new research we discourage people from applying to them. They could fund practice innovation; networks; new models of care; guideline research; doctor-patient communication research; electronic health record research. Jeffrey Borkan, MD, Chair

*University of Connecticut, Department of Family Medicine.*—A general plea for more "investigator initiated" research at AHRQ is very important. Most of their funds recently have been targeted to special initiatives and the new or experienced health services researcher is getting discouraged because there is no money to fund good ideas that develop a line of research. When I was on the study section I saw a lot of good, fundable research go unfunded because of pay lines. This will dry up the pipeline of HSR researchers. The agency's funding level needs to be re-expanded . . . to enable the REAL health services research and quality-of-care/outcomes research to proceed (especially as there is, more than ever, a huge need to restructure the delivery of healthcare, and a need to measure the outcomes of those changes) Rob Cushman, MD Chair, and Judith Fifield, PhD

*Oregon Health and Sciences University, Department of Family Medicine.*—Lately, I know AHRQ has had a difficult time funding K-award for junior researchers. Last year, they went three cycles without funding anyone. This lack of funding will have a grave affect on building the research infrastructure for primary care and health services research. Specific to R03 and R01 awards, they have been unable to fund countless worthy projects. In Oregon, we've had a lot of State policy experiments that desperately need further study, but applications to AHRQ have been rejected. Jennifer E. DeVoe, MD, DPhil

#### NATIONAL INSTITUTES OF HEALTH (NIH)

This is the first time that our organizations have made a request for funding for the NIH. Historically, much of the work that has been done at NIH hasn't been open to the kinds of questions that family medicine researchers have been concerned about. We are encouraged by the development of the NIH Roadmap and the Clinical and Translational Science Awards (CTSA), along with the establishment, in statute, of a funding stream for the common fund that NIH is moving to becoming a more fertile arena for family medicine and other primary care research. Hence, we support the Ad Hoc Group for Medical Research and others' call for an increase in NIH

funding by 6.7 percent in each of the next 3 years. However, there are major strides we believe NIH needs to make to ensure that the promise of bench to bedside research truly becomes bench to bedside to community—and back. What do we mean by that? In their own words:

*University of Connecticut, Department of Family Medicine.*—Adding more “action research”, in which the community (including, but not exclusively, the community clinicians) participates more in the definition of the problem, the design of the solution, and the dissemination and management of the results as they evolve, could augment the impactfulness of the eventual findings. Rob Cushman, MD, Chair

*University of Buffalo, Department of Family Medicine.*—I think Family Medicine would like to see more opportunities for PBRN and community based participatory research approaches to further the translation of research from bedside to patient. In parallel, current study sections are heavily weighted with bench and clinical trial researchers. Having more family medicine researchers participate on review boards will help get more of these types of grants funded. Tom Rosenthal, MD, Chair

*University of Massachusetts, Department of Family Medicine and Community Health.*—As for NIH, trying to sell real-world interventions that may not be scientifically pure but answer relevant questions for improving care to study sections remains a challenge. Many editorials have been written about the lack of applicability of much RCT evidence to real-world practice situations because the populations have been so carefully selected that they are not remotely representative of primary care patients. Furthermore, for primary care researchers, the need to choose a disease or organ and focus narrowly to succeed at NIH is quite problematic—research affecting primary care needs to focus on patients, providers, and processes . . . Barry Saver, MD, MPH

#### CONCLUSION

We hope that the committee will be able, with the more generous figures included in the fiscal year 2008 House and Senate Budget Resolutions this year, to fund increases in these three important programs: health professions primary care medicine and dentistry training, AHRQ, and NIH. Certainly, at a minimum, we request that funding cuts to the health professions primary care medicine and dentistry training program be restored to at least fiscal year 2005 levels of \$88.8 million. As a reminder however, these programs were funded at a historic high of \$93 million in fiscal year 2002, and we support a return to that figure.

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#### PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH AND WOMEN'S HEALTH RESEARCH COALITION

On the behalf of the Society for Women's Health Research and the Women's Health Research Coalition, we are pleased to submit the following testimony in support of Federal funding of biomedical research at NIH and, more specifically, an investment into women's health research.

The Society for Women's Health Research is the only national non-profit women's health organization whose mission is to improve the health of women through research, education, and advocacy. Founded in 1990, the Society brought to national attention the need for the appropriate inclusion of women in major medical research studies and the need for more information about conditions affecting women disproportionately, predominately, or differently than men. In 1999, the Women's Health Research Coalition was created by the Society as a grassroots advocacy effort consisting of scientists, researchers, and clinicians from across the country that are concerned and committed to improving women's health research.

The Society and Coalition are committed to advancing the health of women through the discovery of new and useful scientific knowledge. We believe that sustained funding for biomedical and women's health research programs conducted and supported across the Federal agencies is absolutely essential if we are to meet the health needs of the population and advance the Nation's research capability.

#### NATIONAL INSTITUTES OF HEALTH

From decoding the human genome to elucidating the scientific components of human physiology, behavior, and disease, scientists are unearthing exciting new discoveries which have the potential to make our lives and the lives of our families longer and healthier. The National Institutes of Health (NIH) has facilitated these advances by conducting and supporting our Nation's biomedical research. Congressional investment and support for NIH has made the United States the world leader

in medical research and has provided a direct and significant impact on women's health research and the careers of women scientists over the last decade.

Great strides and advancements have been made since the doubling of the NIH budget from \$13.7 billion in 1998 to \$27 billion in 2003. However, we are concerned that the momentum driving new research has been eroded under the current budgetary constraints. Medical research must be considered an essential investment—an investment in thousands of newly trained and aspiring scientists; an investment to remain competitive in the global marketplace; and an investment in our Nation's health. A large majority of Americans believe they are receiving the highest quality and latest advancements in health care and they depend upon Congress to make a strong investment in biomedical research at NIH to continue that expectation.

Unfortunately, the administration's fiscal year 2008 budget request of \$28.6 billion for NIH is unraveling the successes gained from the doubling of NIH's budget. NIH only truly receives \$28.3 billion in the proposed budget due to the transfer of \$300 million to the Global Fund to Fight HIV/AIDS. Further, the proposed budget actually represents a decrease of \$511 million when compared to the amount provided for NIH research activities in the fiscal year 2007 continuing resolution. Not only does the proposed decrease not keep pace with the inflation rate, but it is lower than that of the Biomedical Research and Development Price Index.

Without a robust budget, NIH will be forced to reduce the number of grants it is able to fund. In this current fiscal year, 500 fewer grants would have been funded by NIH had it not received additional funding under the fiscal year 2007 continuing resolution. The number of new grants funded by NIH has already been dropping steadily since fiscal year 2003 and this trend must stop. This shrinking pool of available grants has a significant impact on scientists who depend upon NIH support to cover their salaries and laboratory expenses to conduct high quality biomedical research. Failure to obtain a grant results in reduced likelihood of achieving tenure. This means that new and less established researchers will be forced to consider other careers, with the end result being the loss of the critical workforce so desperately needed to sustain America's cutting edge in biomedical research.

In order to continue the momentum of scientific advancement and expedite the translation of research from the laboratory to the patient, the Society calls for a 6.7 percent increase over fiscal year 2007 actual budget for the NIH for fiscal year 2008. In addition, we request that Congress strongly encourage the NIH to assure that women's health research receives resources sufficient to meet the health needs of all women.

Scientists have long known of the anatomical differences between men and women, but only within the past decade have they begun to uncover significant biological and physiological differences. Sex-based biology, the study of biological and physiological differences between men and women, has revolutionized the way that the scientific community views the sexes. Sex differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, coronary heart disease, immune dysfunction, mental health disorders, and other illnesses. Congress recognizes the importance of this research and should support NIH at an appropriate level of funding and direct NIH to continue expanding research into sex-based biology.

#### OFFICE OF RESEARCH ON WOMEN'S HEALTH

The NIH Office of Research on Women's Health (ORWH) has a fundamental role in coordinating women's health research at NIH, advising the NIH Director on matters relating to research on women's health; strengthening and enhancing research related to diseases, disorders, and conditions that affect women; working to ensure that women are appropriately represented in research studies supported by NIH; and developing opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. ORWH has a pivotal role within the NIH structure and beyond to maintain and advance not only biomedical research in women's health but also careers of women in science and medicine. ORWH co-chaired a task force with the Director of NIH examining a report by the National Academies of Science regarding women in medicine and science. It is through ORWH that many initiatives can be achieved to strengthen the position of women scientists. Further, ORWH strives to address sex and gender perspectives of women's health and women's health research, as well as differences among special populations of women across the entire life span, from birth through adolescence, reproductive years, menopausal years and elderly years.

Two highly successful programs supported by ORWH that are critical to furthering the advancement of women's health research are Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Re-

search on Sex and Gender Factors Affecting Women's Health (SCOR). These programs benefit the health of both women and men through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment.

The BIRCWH program is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. What makes BIRCWH so unique is that it bridges advanced training with research independence across scientific disciplines. It is expected that each scholar's BIRCWH experience will culminate in the development of an established independent researcher in women's health. The BIRCWH has released four RFAs (1999, 2001, 2004, and 2006). Since 2000, 287 scholars have been trained (76 percent women) in the 24 centers resulting in over 882 publications, 750 abstracts, 83 NIH grants and 85 awards from industry and institutional sources. Each BIRCWH receives approximately \$500,000 a year, most of which comes from the ORWH budget.

The SCOR program, administered by the National Institute of Arthritis and Musculoskeletal and Skin Diseases, was developed by ORWH in 2000 through an initial RFA that resulted in 11 SCOR Centers out of 36 applications. SCORs are designed to increase the transfer of basic research findings into clinical practice by housing laboratory and clinical studies under one roof. The program was designed to complement other federally supported programs addressing women's health issues such as BIRCWH. The eleven SCOR programs are conducting interdisciplinary research focused on major medical problems affecting women and comparing gender difference to health and disease. Each SCOR works hard to transfer their basic research findings into the clinical practice setting. A second RFA is due to be funded in 2007 with virtually no hope of expanding or matching the number of current SCOR programs, due to anticipated budget shortfalls. Each program costs approximately \$1 million per year.

Despite the advancement of women's health research and ORWH's innovative programs to advance women scientists, it received a \$15,000 decrease for fiscal year 2007 after having also received a cut of \$249,000 for fiscal year 2006 from the Office of the Director. It is unconscionable to cut the funds from this critical program at NIH. This research is vital to women and men and we implore Congress to direct NIH to continue its support of ORWH and its programs.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Department of Health and Human Services (HHS) has several offices that enhance the focus of the government on women's health research. Agencies with offices, advisors or coordinators for women's health or women's health research are the Department of HHS, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Quality and Research, the Indian Health Service, the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, and the Centers for Medicare and Medicaid Services. These agencies need to be funded at levels adequate for them to perform their assigned missions. We ask that the committee report clarify that Congress supports the permanent existence of these various offices and would like to see them appropriately funded to insure that their programs can continue and be strengthened in the coming fiscal year.

#### HHS OFFICE OF WOMEN'S HEALTH

The HHS Office of Women's Health (OWH) is the Government's champion and focal point for women's health issues. It works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. The OWH coordinates women's health efforts in HHS to eliminate disparities in health status and supports culturally sensitive educational programs that encourage women to take personal responsibility for their own health and wellness. An extraordinary program initiated by the OWH is the National Centers of Excellence in Women's Health (CoEs).

Developed in 1996, the CoE's offer a new model for university-based women's health care. Selected on a competitive basis, the current twenty CoEs throughout the country seek to improve the health of all women across the lifespan through the integration of comprehensive clinical health care, research, medical training, community outreach and public education, and medical school faculty leadership development. The CoEs are able to reach a more diverse population of women, including more women of color and women beyond their reproductive years. However, CoEs are vulnerable to pressures of obtaining adequate funding and having to compete for scarce resources. A CoE designation by the OWH is critical not only to patients

and surrounding communities but also to establishing foundation and other non-government funding. The CoEs must continue to exist and must have their funding assured if women are to be able to continue to access quality care through the life cycle. It is our understanding that the funding for CoEs is being cut in fiscal year 2007 and 2008. This must not happen.

In fiscal year 2006, OWH received a \$1 million decrease in its budget, bringing it to \$28 million, and in fiscal year 2007 under the continuing resolution it was flat funded at the fiscal year 2006 level. The President's proposed fiscal year 2008 budget decreases OWH funding by \$1 million again, bringing the budget down to \$27 million. We urge Congress to provide an increase of \$2 million for the HHS OWH, to bring funding back up to the fiscal year 2005 level. This will allow OWH to continue and to sustain and expand the National Centers of Excellence in Women's Health.

#### AGENCY FOR HEALTHCARE AND RESEARCH QUALITY

The Agency for Healthcare Research and Quality (AHRQ) is the lead Public Health Service Agency focused on health care quality, including coordination of all Federal quality improvement efforts and health services research. AHRQ's work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of health care. This important information provided by AHRQ is brought to the attention of policymakers, health care providers, and consumers who can make a difference in the quality of health care that women receive.

AHRQ has a valuable role in improving health care for women. Through AHRQ's research projects and findings, lives have been saved and underserved populations have been treated. For example, women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines that have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks.

While AHRQ has made great strides in women's health research, the administration's budget for fiscal year 2008 could threaten such life-saving research. Even with the administration's proposed budget for fiscal year 2008, which includes an \$11 million increase, this does not address the major shortfall which this Agency has been operating under for years. Furthermore, this budget increase is targeted for a specific program and does not help to address the lack of funding that the women's health office has experienced for years. If instead a budget of \$319 million were enacted, AHRQ would be virtually flat funded for the fifth year in a row at fiscal year 2007 levels. Flat funding seriously jeopardizes the research and quality improvement programs that Congress demands or mandates from AHRQ.

We encourage Congress to fund AHRQ at \$443 million for fiscal year 2008. This will ensure that adequate resources are available for high priority research, including women's health care, gender-based analyses, Medicare, and health disparities.

In conclusion, Mr. Chairman, we thank you and this committee for its strong record of support for medical and health services research and its unwavering commitment to the health of the Nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

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#### PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION

##### SUMMARY

On behalf of the more than 70,000 individuals and their families who are affected by Spina Bifida—the Nation's most common, permanently disabling birth defect—the Spina Bifida Association (SBA) appreciates the opportunity to submit written testimony for the record regarding fiscal year 2008 funding for the National Spina Bifida Program and other related Spina Bifida initiatives.

SBA respectfully requests that the subcommittee provide the following allocations in fiscal year 2008 to help improve quality-of-life for people with Spina Bifida:

(1) \$7 million to the National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) to support existing program initiatives and allow for the further development of the National Spina Bifida Patient Registry; and

(2) \$200,000 to the Agency for Healthcare and Quality to support its validation of quality patient treatment data measures for the National Spina Bifida Patient Registry.

As you may know, these funding requests are supported by a broad bipartisan group of Members of Congress, including congressional Spina Bifida caucus leaders, Representatives Bart Stupak, Chris Smith, Ileana Ros-Lehtinen, and Dan Burton, among many others.

#### COST OF SPINA BIFIDA

It is important to note that the lifetime costs associated with a typical case of Spina Bifida—including medical care, special education, therapy services, and loss of earnings—are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare Programs. Our Nation must do more to help reduce the emotional, financial, and physical toll of Spina Bifida on the individuals and families affected. Efforts to reduce and prevent suffering from Spina Bifida help to save money and save lives.

#### IMPROVING QUALITY-OF-LIFE THROUGH THE NATIONAL SPINA BIFIDA PROGRAM

SBA has worked with Members of Congress to ensure that our Nation is taking all the steps possible to prevent Spina Bifida and diminish suffering for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. The National Spina Bifida Program at the CDC works on two critical levels—to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the 70,000 individuals and families affected by Spina Bifida. Moreover, the National Spina Bifida Program works to improve the outlook for a life challenged by this complicated birth defect—principally identifying valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need.

The National Spina Bifida Program serves as a national center for information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergy, obesity, skin breakdown and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. All of these problems can be treated or prevented, but only if those affected by Spina Bifida—and their caregivers—are properly educated and taught what they need to know to maintain the highest level of health and well-being possible. The National Spina Bifida Program's secondary prevention activities represent a tangible quality-of-life difference to the 70,000 individuals living with Spina Bifida with the goal being living well with Spina Bifida.

One way to increase research in Spina Bifida, improve quality and save precious resources is to establish a patient registry for Spina Bifida. Plans are underway to create the National Spina Bifida Patient Registry intended to determine both the best practices clinically and the cost effectiveness of treatment of Spina Bifida and the support the creation of quality measures to improve care overall. It is only through research towards improved care that we can truly save lives while realizing a significant cost savings.

In fiscal year 2007, SBA requested \$6 million be allocated to the National Spina Bifida Program to support and expand the National Spina Bifida Program. Although the House version of the fiscal year 2007 LHHS appropriations bill provided the \$6 million request; the fiscal year 2007 Continuing Appropriations Resolution provided \$5.025 million (level funding) for this program. SBA understands and appreciates that the Congress and the Nation face difficult budgetary challenges. However, the progress being made by the National Spina Bifida Program must be sustained and expanded to ensure that people with Spina Bifida—over the course of their lifespan—have the support and access to quality care they need and deserve. To that end, SBA advocates that Congress allocate \$7 million in fiscal year 2008 to the National Spina Bifida Program it can continue its current scope of the work and increase its folic acid awareness and Spina Bifida prevention efforts, further develop the National Spina Bifida Patient Registry, and sustain the National Spina Bifida

Clearinghouse and Resource Center. Increasing funding for the National Spina Bifida Program will help ensure that our Nation continues to mount a comprehensive effort to prevent and reduce suffering from Spina Bifida.

#### PREVENTING SPINA BIFIDA

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty-five million women are at-risk of having a child born with Spina Bifida and each year approximately 3,000 pregnancies in this country are affected by Spina Bifida, resulting in 1,500 births. The consumption of 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce incidence of Spina Bifida up to 75 percent. There are few public health challenges that our Nation can tackle and conquer by three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 25 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age—particularly those most at-risk for a Spina Bifida pregnancy—consume adequate amounts of folic acid prior to becoming pregnant.

The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain diet rich in folic acid. Since 1968, the CDC has led the Nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. This public health success should be celebrated, but it is only half of the equation as approximately 3,000 pregnancies still are affected by this devastating birth defect. The Nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call—such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBA works collaboratively with CDC, the March of Dimes and the National Council on Folic Acid to increase awareness of the benefits of folic acid, particular for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves or those who have already conceived a baby with Spina Bifida). With additional funding in fiscal year 2008 these activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBA advocates that Congress provide additional funding to CDC to allow for a particular public health education and awareness focus on at-risk populations (e.g. Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a \$7 million fiscal year 2008 allocation for the National Spina Bifida Program, SBA supports a fiscal year 2008 allocation of \$137.6 million for the NCBDDD so the agency can enhance its programs and initiatives to prevent birth defects and developmental disabilities and promote health and wellness among people with disabilities.

#### IMPROVING HEALTH CARE FOR INDIVIDUALS WITH SPINA BIFIDA

The mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the outcomes and quality of health care; reduce its costs; improve patient safety; decrease medical errors; and broaden access to essential health services. The work conducted by the agency is vital to the evaluation of new treatments in order to ensure that individuals and their families living with Spina Bifida continue to receive the high quality health care that they need and deserve—SBA urges the subcommittee to allocate \$200,000 in fiscal year 2008 to AHRQ so the agency can continue to support and expand the development of a National Spina Bifida Patient Registry. This funding will allow AHRQ to direct and lead the effort to validate quality patient treatment data measures for the National Spina Bifida Patient Registry, which will help improve the quality of care provided throughout the Nation's system of Spina Bifida Clinics. In addition, SBA recommends that AHRQ receive an overall funding allocation of \$350 million in fiscal year 2008 so that it can continue to conduct follow-up efforts to evaluate Spina Bifida treatments and sustain and expand its myriad initiatives to improve quality of health care throughout the Nation.

#### SUSTAIN AND SEIZE SPINA BIFIDA RESEARCH OPPORTUNITIES

Our Nation has benefited immensely from our past Federal investment in biomedical research at the National Institutes of Health (NIH). SBA joins with the rest of the public health and research community in advocating that NIH receive a 6.7

percent increase (\$30.869 billion) in fiscal year 2008. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA requests that the subcommittee include language in the report accompanying the fiscal year 2008 LHHS measure to:

- Urge the National Institute of Child Health and Human Development (NICHD)—expansion of its role—and support of—a more comprehensive Spina Bifida research portfolio;
- Commend the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for its interest in exploring issues related to the neurogenic bladder and to encourage the institute to forge ahead with its work in this important topic area; and
- Encourage the National Institute of Neurological Diseases and Stroke (NINDS) to continue and expand its research related to the treatment and management of hydrocephalus.

#### CONCLUSION

SBA stands ready to work with the subcommittee and other Members of Congress to advance policies that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views on funding for programs that will improve the quality-of-life for the 70,000 Americans and their families living with Spina Bifida and stand ready to answer any questions you may have.

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#### PREPARED STATEMENT OF THE AIDS INSTITUTE

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the fiscal year 2008 Labor, Health, and Education and Related Services appropriation measure. We thank you for your consistent support of these programs over the years, and trust you will do your best to adequately fund them in the future in order to provide for, and protect the health of many Americans.

#### HIV/AIDS

HIV/AIDS remains one of the world's worst health pandemics in history. In the United States, according to the CDC, an estimated 1.2 million people have been infected, 40,000 new infections each occur each year, and 531,000 people have died.

Persons of minority races and ethnicities are disproportionately affected by HIV/AIDS. African Americans, who make up approximately 13 percent of the United States population, account for half of the HIV/AIDS cases. HIV/AIDS also disproportionately affects the poor, and about 70 percent of those infected rely on public health care financing.

The U.S. Government has played a leading role in fighting AIDS, both here and abroad. The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically and a portion of our Nation's contribution to the global AIDS effort are funded through your subcommittee. The AIDS Institute, working in coalition with other AIDS organizations, have developed funding request numbers for each of these domestic and global AIDS programs. The AIDS Institute asks that you do your best to adequately fund these programs at the requested level.

We are keenly aware of budget constraints and competing interests for limited dollars. Unfortunately, despite the growing need, almost all domestic HIV/AIDS programs in recent years have experienced funding decreases, and in fiscal year 2007 all programs except one part of the Ryan White program were flat funded by the Joint Resolution.

This year, the President has proposed increases to three new domestic HIV/AIDS programs: \$25 million for the AIDS Drug Assistance Program (ADAP); \$6.3 million for early treatment Ryan White programs; and \$63 million for HIV testing. The AIDS Institute applauds this and encourages the committee to fund them. The President has proposed a \$6 million decrease for Ryan White AIDS Education and Treatment Centers (AETCs) and \$30 million to implement the Early Diagnosis Grant Program. The AIDS Institute opposes these proposals and asks you to as well.

## RYAN WHITE CARE ACT

[In millions of dollars]

	Amount
Fiscal year:	
2007 .....	2,112
2008 President's Request .....	2,133
2008 Community Request .....	2,794

The centerpiece of the government's response to caring and treating low-income individuals with HIV/AIDS are those programs funded under the Ryan White CARE Act. CARE Act programs currently reach over 571,000 low-income, uninsured, and underinsured people each year. Providing care and treatment for those who have HIV/AIDS is not only compassionate, but is cost-effective in the long run, and serves as a tool in prevention of HIV/AIDS.

In fiscal year 2007, all programs except Part B base funding, were flat funded. This is on top of many years of funding decreases, except for minor increases for ADAP. It is now time to reverse these funding decreases and provide these vitally important programs with the community requested level of funding. Consider the following:

(1) Caseload levels are increasing. People are living longer due to lifesaving medications; there are 40,000 new infections each year; and the CDC has recommended routine voluntary HIV testing in all healthcare settings for everyone from the ages of 13 to 64. CDC estimates its proposed \$63 million testing initiative will result in 31,000 new infections being diagnosed. All of this will necessitate the need for more CARE Act services and medications.

(2) The price of healthcare, including medications, is increasing and Medicaid benefits are being scaled-back at both the State and Federal levels.

(3) Funding under the recently reauthorized CARE Act is being distributed through a different formula which, without additional funding, will result in many cities and States losing funding. While some jurisdictions are experiencing increases, others are receiving decreases. Congress can help limit the drastic funding losses caused by formula changes by increasing the overall funding levels.

(4) ADAP funding shortfalls are causing States to place clients on waiting lists, limiting drug formularies, and increasing eligibility requirements. In January 2007, four States reported having waiting lists, totaling 558 people. In the State of South Carolina there are 540 people on its waiting list. Six other ADAPs reported other cost containment measures, including three with capped enrollment and others with formulary reductions, eligibility restrictions and limiting annual client expenditures. Since ADAP received no increase last year and a mere \$2.2 million the year before, severe restrictions are anticipated in many States across the country.

(5) Two reports conclude there are a staggering number of people in the United States who are not receiving life-saving AIDS medications. The Institute of Medicine report "Public Financing and Delivery of HIV/AIDS Care, Securing the Legacy of Ryan White" concluded that 233,069 people in the United States who know their HIV status do not have continuous access to antiretrovirals. A study by the CDC titled, "Estimated number of HIV-infected persons eligible for and receiving antiretroviral therapy, 2003 United States", reached similar conclusions. According to the CDC, 212,000, or 44 percent of eligible people living with HIV/AIDS, aged 15–49 in the United States, are not receiving antiretroviral therapy.

*Fiscal Year 2007 Administration Proposals.*—While we appreciate the \$25 million increase for ADAP proposed by the administration, it is far from the \$233 million that is truly needed. As we seek to provide lifesaving medications to those abroad, we must ensure we are providing medications to our own in the United States. The administration has also proposed to increase funding for Part C (Title III) early treatment programs by \$6.3 million. Again, while this increase is appreciated, it is far short of the increased need of \$88 million for funding over 360 community-based primary health clinics and public health providers.

The President has proposed an unprecedented decrease of \$6 million for AIDS Education and Treatment Centers (AETCs), which train more than 100,000 people per year. The new CARE Act now requires them to add trainings on Hepatitis B and C and culturally competent training for Native American and Alaska Native populations. To meet current needs, AETCs require a \$15.3 million increase.

Funding increases for other Ryan White CARE Act programs are also urgently needed. While patient caseloads increase, over the past 5 years, Part A (Title I) has been cut by \$15 million, over the past 4 years Part C (Title III) has been cut by \$5 million, and Part D (Title IV) by \$2 million.

Part A, which used to cover 51 urban areas most affected by HIV/AIDS, now includes 56 areas, but received no increased funds, meaning there will be less money to go around. They are requesting an increase of \$236 million. Part B Base, which provides funds to the States received an increase of \$70 million in fiscal year 2007, but still lacks the adequate levels and is requesting an increase of \$57 million.

Title IV, which funds HIV care, psychosocial and other essential services to women, infants, children and youth, is requesting an increase of \$46 million. The AIDS Institute also supports an increase of \$6 million to Dental Reimbursement and Partnerships Programs.

The AIDS Institute supports continued and increased funding for the Minority AIDS Initiative (MAI). MAI funds services nationwide that address the disproportionate impact that HIV has on communities of color.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION—HIV PREVENTION AND SURVEILLANCE

[In millions of dollars]

	Amount
Fiscal year:	
2007 .....	652
2008 President's Request .....	745
2008 Community Request .....	1,049

While the number of new HIV infections in the United States has greatly decreased since the 1980's, there are still an estimated 40,000 new infections each year. As with other domestic AIDS programs, prevention funding is severely lagging and CDC's AIDS funding has declined in the last 5 years. It is not surprising given the budget decreases, the goal of reducing the infection rate in half by 2005 was not reached.

*Fiscal Year 2008 Administration Proposals.*—The AIDS Institute is in strong support of the President's proposed increase of \$63 million to support HIV testing of more than 2 million people, mostly African-Americans, in 10 jurisdictions with the highest rates of new infections, as well as the incarcerated and injecting drug users. Knowledge of one's HIV status, particularly for high risk individuals, is an effective prevention tool. Approximately one-quarter of the over 1 million people living with HIV in the United States (252,000 to 312,000 persons) are unaware of their HIV status. This initiative should help prevent future infections and bring more people into lifesaving treatment and care. The AIDS Institute urges the committee to fund this extremely worthy program.

The administration is also proposing \$30 million to implement the Early Diagnosis Grant Program, as called for by the new CARE Act. No State currently meets the grant conditions, which go beyond current CDC testing recommendations. We recommend that this funding be spent on other CDC HIV/AIDS prevention programs.

While The AIDS Institute supports increased testing programs, we do not support funding these efforts at the expense of prevention intervention programs, which are already under funded.

Efforts to improve prevention methods and weed out non-effective programs should be a constant undertaking and be guided by science and fact based decision-making. It is for these reasons The AIDS Institute opposes abstinence-only until marriage programs, for which the President requested a \$28 million increase. While we support abstinence-based prevention programs as part of a comprehensive prevention message, there is no scientific proof that abstinence-only programs are effective. On the contrary, they reject proven prevention tools, such as condoms, and fail to address the needs of homosexuals, who can not marry, and who remain greatly impacted by HIV/AIDS.

#### NATIONAL INSTITUTES OF HEALTH—AIDS RESEARCH

[In millions of dollars]

	Amount
Fiscal year:	
2007 .....	2,903
2008 President's Request .....	2,905
2008 Community Request .....	3,200

Through the NIH, research is conducted to understand the AIDS virus and its complicated mutations; discover new drug treatments; develop a vaccine and other prevention programs such as microbicides; and ultimately, a cure. Much of this work at the NIH is done in cooperation with private funding. The critically important work performed by the NIH not only benefits those in the United States, but the entire world.

This research has already helped in the development of many highly effective new drug treatments, prolonging the lives of millions of people. As neither a cure nor a vaccine exists, and patients continue to build resistance to existing medications, additional research must continue. We ask the committee to fund critical AIDS research at the community requested level of \$3.2 billion.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Many persons infected with HIV also experience drug abuse and/or mental health problems, and require the programs funded by SAMHSA. Given the growing need for services, we are disappointed by proposed funding cuts at SAMHSA, including \$47 million for the Center for Substance Abuse Treatment, \$36 million for the Center for Substance Abuse Prevention, and \$76 million for the Center for Mental Health Services. We ask the committee to reject these cuts, and adequately fund these programs

#### VIRAL HEPATITIS

Viral Hepatitis, whether A, B, or C, is an infectious disease that also deserve increased attention by the Federal Government. According to the CDC, there are an estimated 1.25 million Americans chronically infected with Hepatitis B, and 60,000 new infections each year. Although there is no cure, a vaccine is available, and a few treatment options are available. An estimated 4.1 million (1.6 percent) Americans have been infected with Hepatitis C, of whom 3.2 million are chronically infected. Currently, there is no vaccine and very few treatment options. It is believed that one-third of those infected with HIV are co-infected with Hepatitis C.

Given these numbers, we are disappointed the administration is calling for continued level funding of \$17.5 million for Viral Hepatitis at the CDC. This amount is less than what was funded in fiscal year 2003 and falls short of the \$50 million that is needed. These funds are needed to establish a program to lower the incidence of Hepatitis through education, outreach, and surveillance, and to support such initiatives as the CDC National Hepatitis C Prevention Strategy and the 2002 NIH Consensus Statement on the Management of Hepatitis C and accompanying recommendations.

The administration is proposing to cut the 317 Immunization Grant Program funds that serve as the major source in the public sector for at-risk adult immunizations. Instead of facing cuts, this cost-effective program should be significantly enhanced in order to protect people from Hepatitis A and B. We recommend funding the 317 Program at \$802 million for fiscal year 2008 in order to fully realize the public health benefits of immunization.

The AIDS Institute asks that you give great weight to our testimony and remember it as you deliberate over the fiscal year 2008 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Director of Federal Affairs, The AIDS Institute, 1705 DeSales Street, NW, Washington, DC 20036; (202) 462-3042; cschmid@theaidsinstitute.org. Thank you very much.

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#### PREPARED STATEMENT OF THE HUMANE SOCIETY LEGISLATIVE FUND

The Humane Society Legislative Fund (HSLF) supports a strong commitment by the Federal Government to research, development, standardization, validation and acceptance of non-animal and other alternative test methods. We are also submitting our testimony on behalf of The Humane Society of the United States and The Procter & Gamble Company. Thank you for the opportunity to present testimony relevant for the fiscal year 2008 budget request for the National Institute of Environmental Health Sciences (NIEHS) for the fiscal year 2008 activities of the National Toxicology Program Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM), the support center for the Interagency Coordinating Committee for the Validation of Alternative Test Methods (ICCVAM).

In 2000, the passage of the ICCVAM Authorization Act into Public Law 106-545, created a new paradigm for the field of toxicology. It requires Federal regulatory agencies to ensure that new and revised animal and alternative test methods be scientifically validated prior to recommending or requiring use by industry. An inter-

nationally agreed upon definition of validation is supported by the 15 Federal regulatory and research agencies that compose the ICCVAM, including the EPA. The definition is: "the process by which the reliability and relevance of a procedure are established for a specific use."

#### FUNCTION OF THE ICCVAM

The ICCVAM performs an invaluable function for regulatory agencies, industry, public health and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the Federal regulatory agencies that regulate the particular endpoint the test measures. In turn, the Federal agencies maintain their authority to incorporate the validated test methods as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulator burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test methods. In addition, from the perspective of animal protection advocates, ICCVAM can serve to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce or replace animals, should be expeditiously integrated into Federal toxicological regulations, requirements and recommendations.

#### HISTORY OF THE ICCVAM

The ICCVAM is currently composed of representatives from the relevant Federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for NIEHS to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to Federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97-3981, "Validation and Regulatory Acceptance of Toxicological Test Methods." This report, and subsequent revisions, has become the sound science guide for consideration of new, revised and alternative test methods by the Federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' NICEATM. Representatives from Federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, several methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. In addition, the ICCVAM is working to streamline assessment of methods from the European Union (EU) that have already been validated for use within the EU. The open public comment process, input by interested stakeholders and the continued commitment by the Federal agencies has led to ICCVAM's success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

#### REQUEST FOR COMMITTEE REPORT LANGUAGE

In 2006, the NICEATM/ICCVAM at the request of the U.S. Congress began a process of developing a 5-year roadmap for assertively setting goals to prioritize ending the use of antiquated animal tests for specific endpoints. The HSLF and other national animal protection organizations provided extensive comments on the process and priorities for the roadmap.

While the stream of methods forwarded to the ICCVAM for assessment has remained relatively steady, it is imperative that the ICCVAM take a more proactive role in isolating areas where new methods development is on the verge of replacing animal tests. These areas should form a collective call by the Federal agencies that compose ICCVAM to fund any necessary additional research, development, validation and validation assessment that is required to eliminate the animal methods. We also strongly urge the NICEATM/ICCVAM to closely coordinate research, development and validation efforts with its European counterpart, the European Centre

for the Validation of Alternative Methods (ECVAM) to ensure the best use of available funds and sound science. This coordination should also reflect a willingness by the Federal agencies comprising ICCVAM to more readily accept validated test methods proposed by the ECVAM to ensure industry has a uniform approach to worldwide chemical safety evaluation.

We respectfully request the subcommittee consider the following report language for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations bill to ensure that the 5-year roadmap is completed in a timely manner:

“The committee commends the National Interagency Center for the Evaluation of Alternative Methods/Interagency Coordinating Committee on the Validation of Alternative Methods (NICEATM/ICCVAM) for commencing a process for developing a 5-year plan to research, develop, translate and validate new and revised non-animal and other alternative assays for integration of relevant and reliable methods into the Federal agency testing programs. The 5-year plan shall be used to prioritize areas, including tiered testing and evaluation frameworks, which have the potential to most significantly and rapidly reduce, refine or replace laboratory animal methods. The committee directs a transparent, public process for developing this plan and recommends the plan be presented to the committee by November 15, 2007. Funding for completing the 5-year plan shall not reduce the NICEATM/ICCVAM appropriation.”

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#### PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

On behalf of The Humane Society of the United States (SUS) and our more than 10 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priority for the Labor, Health and Human Services, Education and Related Agencies Subcommittee in fiscal year 2008. We are also submitting our testimony on behalf of The Humane Society Legislative Fund (HSLF). Thank you for the opportunity to present testimony relevant for the fiscal year 2008 budget request.

#### BREEDING OF CHIMPANZEES FOR RESEARCH

The HSUS requests that no Federal funding be appropriated for breeding of chimpanzees for research, or for research that requires breeding of chimpanzees, for the following reasons:

- The National Center for Research Resources has a publicly-declared moratorium (extended until December 2007) on breeding chimpanzees which prohibits breeding of federally owned or supported chimpanzees or NIH funding of projects that require chimpanzee breeding (NCRR written communication, February 28, 2006).
- The United States currently has a surplus of chimpanzees available for use in research due to overzealous breeding for HIV research and subsequent findings that they are a poor HIV model.<sup>1</sup>
- The cost of maintaining chimpanzees in laboratories is exorbitant, totaling between \$4.7 and \$9.3 million each year for the current population of approximately 800 federally owned or supported chimpanzees (\$15–39 per day per chimpanzee; \$500,000 per chimpanzee's 50-year lifetime). Breeding of additional chimpanzees into laboratories will only perpetuate a number of burdens on the government—up to 60 years per chimpanzee born into the system.
- Expansion of the chimpanzee population in laboratories only creates more concerns than presently exist about their quality of care.
- Use of chimpanzees in research raises strong public concerns.

#### BACKGROUND AND HISTORY

Beginning in 1995, the National Research Council (NRC) confirmed a chimpanzee surplus and recommended a moratorium on breeding of federally owned or supported chimpanzees,<sup>1</sup> who now number approximately 800 of the 1,300 total chimpanzees available for research in the United States. According to a National Research Resources Advisory Council September 15, 2005 meeting, the National Center for Research Resources (NCRR) of NIH extended the moratorium until December 2007 because of high costs of chimpanzee care, lack of existing colony information, and failure of chimpanzees as a model, such as for HIV. Further, it has also been

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<sup>1</sup>NRC (National Research Council) (1997) Chimpanzees in research: strategies for their ethical care, management and use. National Academies Press: Washington, D.C.

noted that “a huge number” of chimpanzees were not being used in active research protocols and were therefore “just sitting there.”<sup>2</sup> NCRR will be making a decision this year as to whether the breeding moratorium should continue. There is no justification for breeding of additional chimpanzees for research; therefore The HSUS hopes that NCRR will continue the moratorium into the future. Importantly, however, lack of Federal funding for breeding will ensure that no breeding of federally owned or supported chimpanzees for research will occur in fiscal year 2008.

Furthermore, despite the moratorium on breeding, there are cases in which the moratorium is not being obeyed, further prompting the need for congressional action.

#### DEVIATIONS FROM THE MORATORIUM

Despite the NCRR breeding moratorium, which prohibits breeding of federally owned or supported chimpanzees or NIH funding of projects that require chimpanzee breeding (NCRR written communication, February 28, 2006), chimpanzee breeding is still being funded by NIH. For example, the National Institute of Allergy and Infectious Diseases maintains a contract with New Iberia Research Center in Louisiana to provide 10 to 12 infant chimpanzees annually for research projects. The 10-year contract entitled “Leasing of chimpanzees for the conduct of research” has been allotted over \$22 million, with \$3.9 million awarded since its inception in September 2002.

#### CONCERNS REGARDING CHIMPANZEE CARE IN LABORATORIES

Inspections conducted by the U.S. Department of Agriculture demonstrate that basic chimpanzee housing requirements are often not being met. Inspection reports for three federally funded chimpanzee facilities reported housing of chimpanzees in less than minimal space requirements, inadequate environmental enhancement for primates, and/or general disrepair of facilities. Problems at three major chimpanzee research facilities add further argument against the breeding of even more chimpanzees.

#### CHIMPANZEES HAVE OFTEN BEEN A POOR MODEL FOR HUMAN HEALTH RESEARCH

The scientific community recognizes that chimpanzees are poor models for HIV because chimpanzees do not develop AIDS. Similarly, though chimpanzees do not model the course of the human Hepatitis C virus, they continue to be widely used for this research. According to the chimpanzee genome, some of the greatest differences between chimpanzees and humans relate to the immune system,<sup>3</sup> calling into question the validity of infectious disease research using chimpanzees.

#### ETHICAL AND PUBLIC CONCERNS ABOUT CHIMPANZEE RESEARCH

Chimpanzee research raises serious ethical issues, particularly because of their extremely close similarities to humans in terms of intelligence and emotions. Americans are clearly concerned about these issues: 90 percent believe it is unacceptable to confine chimpanzees individually in government-approved cages; 71 percent believe that chimpanzees who have been in the laboratory for over 10 years should be sent to sanctuary for retirement (chimpanzees can live to be 60 years old);<sup>4</sup> and 54 percent believe that it is unacceptable for chimpanzees to “undergo research which causes them to suffer for human benefit.”<sup>5</sup>

We respectfully request the following committee bill or report language: “The committee directs that no funds provided in this act be used to support the breeding of chimpanzees for research or to support research that requires breeding of chimpanzees.”

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for fiscal year 2008. We hope the committee will be able to accommodate this modest request that will save the government a substantial sum of money, benefit chimpanzees, and allay some concerns of the public at large. Thank you for your consideration.

<sup>2</sup> Cohen, J. (2007) Biomedical Research: The Endangered Lab Chimp. *Science*. 315:450–452.

<sup>3</sup> The Chimpanzee Sequencing and Analysis Consortium/Mikkelsen, TS, et al., (1 September 2005) Initial sequence of the chimpanzee genome and comparison with the human genome, *Nature* 437, 69–87.

<sup>4</sup> 2006 poll conducted by the Humane Research Council for Project Release & Restitution for Chimpanzees in laboratories.

<sup>5</sup> 2001 poll conducted by Zogby International for the Chimpanzee Collaboratory.

## PREPARED STATEMENT OF THE TRUST FOR AMERICA'S HEALTH

Trust for America's Health (TFAH), a national non-profit, nonpartisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority, is pleased to provide the subcommittee with the following testimony. In order to provide the resources to build a 21st century public health system that gives all communities a strong defense against today's health threats, TFAH identifies a number of programs essential to achieving this goal.

## BOLSTERING THE NATION'S ABILITY TO DETECT AND CONTROL INFECTIOUS DISEASES SUCH AS PANDEMIC INFLUENZA

*Pandemic Preparedness (\$1.542 billion, \$350 million over the President's request).*—In November 2005, the President requested a total of \$7.1 billion to respond to an influenza pandemic. To date, Congress has appropriated just over \$6 billion of that request. We were pleased that the fiscal year 2008 budget proposal would honor that commitment with an additional \$1.2 billion for pandemic preparedness activities, including making improvements in vaccine technology and manufacturing; stockpiling antivirals, diagnostics and medical supplies; developing contingency planning; enhancing risk communication; and enhancing global and domestic health surveillance.

The emergency supplemental passed by the House and Senate contains \$625 million of the \$870 in one-time pandemic flu funding recommended in the President's fiscal year 2008 budget proposal, primarily for purchasing antiviral medications and medical supplies. In addition, there is a need for an ongoing annual investment, particularly at the CDC, to ensure that preparedness efforts are sustained and effective. These activities require funding beyond the life cycle of the supplemental appropriations vehicles. TFAH supports the remaining \$245 million in one-time pandemic flu funding not included in the emergency supplemental; and \$322 million for ongoing pandemic preparedness activities in the Department of Health and Human Services, which includes \$158 million at the CDC.

Further, we support \$350 million in annual recurring funding for State and local pandemic preparedness activities. States would use this funding to exercise response plans, make revisions and updates to plans, and build medical surge capacity. In the midst of a pandemic, it could be difficult to shift resources from one part of the country to another, so every jurisdiction must be prepared. In fiscal year 2006, Congress provided \$600 million in one-time funding for State and local pandemic preparedness, but this funding will expire at the end of fiscal year 2007, and no such funds have been requested for fiscal year 2008.

## GLOBAL DISEASE DETECTION

Global surveillance for infectious disease outbreaks is also critical. The CDC's Global Disease Detection initiative aims to recognize infectious disease outbreaks faster, improve the ability to control and prevent outbreaks, and detect emerging microbial threats. In fiscal year 2006, Global Disease Detection centers across the globe help countries investigate numerous outbreaks, including avian influenza, hemorrhagic fever, meningitis, cholera and unexplained sudden death. TFAH recommends funding the Global Disease Detection initiative at \$45 million, which is an increase of \$12.5 million over the President's requested level.

## UPGRADING STATE AND LOCAL BIOTERRORISM PREPAREDNESS

The terrorism events of 2001 and the subsequent anthrax and ricin attacks illustrated the need for a responsive public health system and demonstrated that the existing structure has enormous gaps. The Federal Government took unprecedented first steps towards improved preparedness by providing funding to State and local public health departments to better respond to terrorism. These funds have allowed States and localities to conduct needs assessments, develop terrorism response plans and training activities, strengthen epidemiology and surveillance capabilities, and upgrade lab capacity and communications systems. Yet a great deal of work remains to be done.

*The December 2006 TFAH Report, Ready or Not?*—Protecting the Public's Health from Diseases, Disasters and Bioterrorism, examined 10 key indicators to assess areas of both improvement and ongoing vulnerability in our Nation's effort to protect against bioterrorism. The report found that 5 years after the September 11th and anthrax tragedies, emergency health preparedness is still inadequate in America. To address these shortcomings, we recommend the following:

- State and Local Capacity (\$919 million, \$221 million over the President's request).*—CDC distributes grants to 50 States and four metropolitan areas for public health infrastructure upgrades to respond to acts of terrorism or infectious disease outbreaks. In fiscal year 2008, the President proposes to cut funding for this program by \$125.4 million, a nearly 25 percent cut since fiscal year 2005. This would force health departments to cut staff dedicated to preparedness; laboratories would lose trained personnel and the ability to purchase new technology; and disease surveillance and response efforts would be hindered.
- Hospital Preparedness Grants (\$650 million, \$236 million over the President's request).*—The primary focus of the National Bioterrorism Hospital Preparedness Program is to improve the capacity of the Nation's hospitals and other supporting healthcare entities to respond to bioterrorist attacks, infectious disease epidemics, and other large-scale emergencies by enabling hospitals, EMS, and health centers to plan a coordinated response. The President proposes to cut funding for hospital preparedness grants by \$60 million in fiscal year 2008.

#### CHRONIC DISEASES CONTINUE TO TAKE A TOLL

Chronic diseases account for 70 percent of all deaths in the United States and untold disability and suffering. In fact, five of our top six causes of death—heart disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes—are chronic diseases. The treatment of chronic diseases consumes three-quarters of the \$1.7 trillion the United States spends annually on health care.

Smoking, for example, is the single most preventable cause of death and disease in the United States, causing 440,000 premature deaths annually. And increasingly, obesity is a significant risk factor in such major chronic disease killers as heart disease, stroke and diabetes.

#### FIGHTING THE EMERGING OBESITY EPIDEMIC

The number of overweight and obese individuals has reached epidemic proportions in the United States with 64.5 percent of the adult population being diagnosed as obese (119 million). In the United States, the percentage of young people who are overweight has tripled in the last 20 years. Despite this troubling trend, the President's proposed fiscal year 2008 budget provides no increases for existing obesity-related programs.

- Division of Nutrition and Physical Activity (DNPA) (\$65 million, \$23.6 million over the President's request).*—CDC's grant funding allows State health departments to develop a nutrition and physical activity infrastructure; develop a primary prevention plan for nutrition and physical activity to coordinate and link partners in and out of State government; identify and assess data sources to monitor the burden of obesity; and evaluate the progress and impact of the State plans and intervention projects. Currently, only 28 States receive DNPA grants, 7 at basic implementation, and 21 at capacity-building levels. An increase to \$65 million would fund all 50 States and provide \$5 million for the National Fresh Fruit and Vegetable Nutrition Program.
- School Health Programs (\$75.8 million, \$20 million over the President's request).*—CDC's grant funding assists States in improving the health of children through a school level program that engages families and communities and develops health education, physical education, school meals, health services, healthy school environments, and staff health promotion. Currently, school health programs are funded in only 23 States. The recommended increase of \$20 million would expand the number of States to 40.
- STEPS to a Healthier United States (\$43.6 million, \$17.3 million over the President's request).*—STEPS grants support communities, cities and tribal entities to implement health promotion programs and community initiatives. STEPS works with health care and insurance systems to combat obesity in over 40 communities, cities, and tribal entities. The President's budget proposes to cut funding for STEPS by \$17.2 million.
- Adolescent Health Promotion Initiative (\$17.3 million, equal to the President's request).*—This new initiative aims to help schools encourage regular physical activity, healthy eating, and injury prevention. Schools will have access to the Department of Health and Human Services' (HHS) School Health Index, which they can use to make self-assessments and develop action plans. Schools can apply for one of CDC's approximately 3,600 School Culture of Wellness Grants to help implement their action plans.

## IMMUNIZATION

Immunization through vaccination of children and adults is proven effective as a means to prevent some of the most important infectious diseases. Immunization should remain a high public health priority, and, to ensure that its benefits are fully realized, the Federal Government should increase its commitment to these life saving public health interventions.

*National Immunization Program (\$802.5 million, \$257.5 million over the President's request).*—This program provides for childhood and adult operations/infrastructure grants, the purchase of childhood and adult vaccines, and related prevention activities. Each day, 11,000 babies are born in the United States who will need up to 28 vaccinations before they are 2 years old. Even so, nearly 1 million 2-year-olds do not receive all the recommended doses. Every dollar spent on vaccines saves an extraordinary amount downstream: \$27 with DTaP (Diphtheria, Tetanus and Pertussis), \$26 with MMR (Measles, Mumps and Rubella), and \$15 with Hepatitis B. However, the vaccine cost to fully immunize one child has risen in the past 6 years alone from \$186 to \$570.

Currently, the CDC provides grants to all 50 States, six cities and eight current or former territories to carry out immunization activities. TFAH recommends providing \$802.5 million for the National Immunization Program at CDC. This includes \$720 million for the 317 Immunization Program (\$245 million for State operations/infrastructure grants, and \$475 million for the purchase of childhood vaccines); and \$82.543 million for program operations (\$4.887 million for vaccine tracking and \$77.656 million for prevention activities).

## SUPPORTING OTHER PUBLIC HEALTH TOOLS

TFAH supports additional funding for disease detection and surveillance activities which are vital to stemming an infectious disease outbreak, tracking rises in chronic diseases, or responding to a bioterror event.

*Federal and State public health laboratory capabilities (\$47 million, \$20 million over the President's request).*—Additional funds are needed to upgrade facilities and equipment and to bolster the workforce. This funding is essential if scientists are to have the capability to conduct clinical testing for potentially dangerous chemicals, such as ricin, cyanide, nerve agents, and pesticide exposure or test for novel strains of influenza. Of the suggested \$20 million increase, TFAH recommends that \$10 million be used to enhance State public health laboratory biomonitoring capabilities, with \$10 million used to bolster the intramural CDC lab program.

*Environment and Health Outcome Tracking (\$50 million, \$26 million over the President's request).*—The program links environmental and health data in order to identify problems and effective solutions to reduce the burden of chronic disease. Additional funds would enable the program to fund additional States and local health departments, or order to systematically and comprehensively track respiratory diseases, developmental disorders, birth defects, cancers and environmental exposures to help scientists find answers about causes and cures of these diseases. Further, the program plans to issue a major national report on the environment and health in 2008, and expects to make operational its Web-based environmental tracking system and roll out a report reflecting data from funded States within 2 years.

Mr. Chairman, thank you again for the opportunity to submit testimony on the urgent need to enhance Federal funding for core public health programs.

## PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

For 38 years, United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from throughout the Nation. We are governed by the five tribes located wholly or in part in North Dakota. We are an educational institution that consistently has excellent results, placing Indian people in good jobs and reducing welfare rolls. The Perkins funds constitute about half of our operating budget. We do not have a tax base or State appropriated funds on which to rely.

The request of the United Tribes Technical College Board for the section 117 of the Perkins Act, Tribally Controlled Postsecondary Career and Technical Institutions Program is:

—\$8.5 million or \$1.1 million above the administration's request and the fiscal year 2007 enacted level. Funding under section 117 of the Perkins Act has in recent years it has been distributed on a formula basis.

UTTC Performance Indicators. UTTC has:

—An 87 percent retention rate,

- A placement rate of 95 percent (job placement and going on to 4-year institutions),
- A projected return on Federal investment of 1 to 20 (2005 study comparing the projected earnings generated over a 28-year period of UTTC Associate of Applied Science and Bachelor degree graduates of June 2005 with the cost of educating them.), and
- The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable—10 years or until 2011—and with no stipulations. We are also the only tribal college accredited to offer on-line associate degrees.

*The Demand for our Services is Growing and we are Serving More Students.*—For the 2006–2007 school year we enrolled 1,018 students (an unduplicated count). The majority of our students are from the Great Plains States, an area that, according to the 2003 BIA Labor Force Report, has an Indian reservation jobless rate of 76 percent. UTTC is proud that we have an annual placement rate of 95 percent.

In addition, we have served 254 students during school year 2005–2006 in our Theodore Jamerson Elementary school, and 350 children, birth to 5, were served in the child developments centers for 2005–2006.

*UTTC Course Offerings and Partnerships With Other Educational Institutions.*—We offer 15 vocational/technical programs and award a total of 24 2-year degree and 1-year certificates. We are accredited by the North Central Association of Colleges and Schools.

*Licensed Practical Nursing.*—This is our program with the highest number of students. We have an agreement with the University of North Dakota system that allows our students to transfer their credits to these 4-year nursing programs.

*Medical Transcription and Coding Certificate Program.*—Our newest academic endeavor is our Medical Transcription and Coding Certificate Program which is offered through the college's Exact Med Training program and supported by Department of Labor funds.

*Tribal Environmental Science.*—Our Tribal Environmental Science program is being offered through a National Science Foundation Tribal College and Universities Program grant. The 5-year project supports UTTC in implementing a program that leads to a 2-year Associate of Applied Science degree in Tribal Environmental Science.

*Injury Prevention.*—Through our Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population. We received assistance through Indian Health Service to offer the only degree-granting Injury Prevention program in the Nation. Injuries are the number one cause of mortality among Native people for ages 1–44 and the third for overall death rates.

*Online Education.*—We are working to bridge the “digital divide” by providing web-based education and Interactive Video Network courses from our North Dakota campus to American Indians residing at other remote sites and as well as to students on our campus. This spring semester 2007, we have 61 students registered in online courses, of which 48 students are studying exclusively online (approximately 34 FTE) and 13 are campus-based students. These online students come from the following States: Colorado, Georgia, Hawaii, Idaho, Kentucky, Nebraska, North Dakota, Oklahoma, Oregon, South Dakota, West Virginia, and Wisconsin.

Online courses provide the scheduling flexibility students need, especially those students with young children. We offer online full degree programs in the areas of Early Childhood Education, Injury Prevention, Health Information Technology, Nutrition and Food Service and Elementary Education. All totaled, 156 online course seats are filled by students this semester. Over 50 courses are currently offered online, including those in the Medical Transcription and Coding program and those offered through an MOU with Owens Valley Career Development Center.

Our newest online course is suicidology—the study of suicide, its causes, and its prevention and of the behavior of those to threaten or attempt suicide—and we expect that with additional outreach that there will be a significant demand for this course. We also offer a training program through the Environmental Protection Agency to train environmental professionals in Indian Country. The Indian Country Environmental Hazard Assessment Program is a training course designed to help mitigate environmental hazards in reservation communities.

United Tribes Technical College is accredited by the Higher Learning Commission of the North Central Association of Colleges and Schools to provide associate degrees online. This approval is required in order for us to offer Federal financial aid to students enrolled in these online courses. We are the only tribal college accredited to offer associate degrees online.

*Computer Information and Technology.*—The Computer Support Technician program is at maximum student capacity because of limitations on learning resources

for computer instruction. In order to keep up with student demand and the latest technology, we will need more classrooms, equipment and instructors. Our program includes all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

*Nutrition and Food Services.*—UTTC will meet the challenge of fighting diabetes in Indian Country through education. Indians and Alaska Natives have a disproportionately high rate of type 2 diabetes, and have a diabetes mortality rate that is three times higher than the general U.S. population. The increase in diabetes among Indians and Alaska Natives is most prevalent among young adults aged 25–34, with a 160 percent increase from 1990–2004. Diabetes mortality is 3.1 times higher in the Indian/Alaska Native population than in the general U.S. population (Source: fiscal year 2008 Indian Health Service Budget Justification).

As a 1994 Tribal Land Grant institution, we offer a Nutrition and Food Services Associate of Applied Science degree in an effort to increase the number of Indians with expertise in nutrition and dietetics. Currently, there are only a handful of Indian professionals in the country with training in these areas. Among our offerings is a Nutrition and Food Services degree with a strong emphasis on diabetes education, traditional food preparation, and food safety.

We have also established the United Tribes Diabetes Education Center to assist local tribal communities and our students and staff in decreasing the prevalence of diabetes by providing diabetes educational programs, materials and training. We publish and make available tribal food guides to our on-campus community and to tribes.

*Business Management/Tribal Management.*—Another of our newer programs is business and tribal management designed to help tribal leaders be more effective administrators. We continue to refine our curricula for this program.

*Job Training and Economic Development.*—UTTC is a designated Minority Business Development Center serving Montana, South Dakota and North Dakota. We also administer a Workforce Investment Act program and an internship program with private employers in the region.

Economic Development Administration funding was made available to open a “University Center.” The Center is used to help create economic development opportunities in tribal communities. While most States have such centers, this center is the first-ever tribal center.

*Upcoming Endeavors.*—We continue to seek a Memorandum of Understanding with the BIA’s Police Academy in New Mexico that would allow our criminal justice program to be recognized for the purpose of BIA and Tribal police certification, so that Tribal members from the BIA regions in the Northern Plains, Northwest, Rocky Mountain, and Midwest areas would not have to travel so far from their families to receive training. Our criminal justice program is accredited and recognized as meeting the requirements of most police departments in our region. We also anticipate providing similar training for correctional officers, a vital need in Indian country.

Additionally, we are interested in developing training programs that would assist the BIA in the area of provision of trust services. We have several technology disciplines and instructors that are capable of providing those kinds of services with minimum of additional training.

*Department of Education Study Documents our Facility/Housing Needs.*—The 1998 Carl Perkins Vocational Education and Applied Technology Act required the Department of Education to study the facilities, housing and training needs of our institution. That report was published in November 2000 (“Assessment of Training and Housing Needs within Tribally Controlled Postsecondary Vocational Institutions, November 2000, American Institute of Research”). The report identified the need for \$17 million for the renovation of existing housing and instructional buildings and \$30 million for the construction of housing and instructional facilities. These figures do not take into account the costs of inflation since the study was completed in 2000.

We continue to identify housing as our greatest need. Some families must wait from 1 to 3 years for admittance due to lack of available housing. Since 2005 we have assisted 311 families with off campus housing, a very expensive proposition. In order to accommodate the enrollment increase, UTTC partners with local renters and two county housing authorities (Burleigh, Morton).

UTTC has worked hard to combine sources of funding for desperately needed new facilities—within the past few years we have built a 86-bed single-student dormitory on campus, a family student apartment complex, and a Wellness Center. Sources of funds included the U.S. Department of Education, the U.S. Department of Agriculture, the American Indian College Fund, the Shakopee-Mdewakanton Sioux Tribe, among others. We still have a critical housing shortage and more housing

must be built to accommodate those on the waiting list and to meet expected increased enrollment. We also have housing which needs renovation to meet safety codes.

UTTC has acquired an additional 132 acres of land. We have also developed a master facility plan. This plan includes the development of a new campus on which would be single-student and family housing, classrooms, recreational facilities, offices and related infrastructure. A new campus will address our need for expanded facilities to accommodate our growing student population. It will also enable us to effectively address safety code requirements, Americans with Disabilities Act requirements, and to become more efficient in facility management.

Thank you for your consideration of our request. We cannot survive without the basic core vocational/technical education funds that come through the Department of Education. They are essential to the operation of our campus and to the welfare of Indian people throughout the Great Plains region and beyond.